

# ANNUAL REPORT

European Haemophilia Consortium



2025

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## Commonly used acronyms

<b>AG</b>	Activity Grant	<b>MAG</b>	Medical Advisory Group
<b>CEO</b>	Chief Executive Officer	<b>MEP</b>	Member of the European Parliament
<b>EAHAD</b>	European Association for Haemophilia and Allied Disorders	<b>MH</b>	Mental Health
<b>EDHF</b>	European Dental Hygienist Federation	<b>MDT</b>	Multidisciplinary Team
<b>EHA</b>	European Hematology Association	<b>NMO</b>	National Member Organisation
<b>EHC</b>	European Haemophilia Consortium	<b>NTR</b>	Novel Treatment Review
<b>EMA</b>	European Medicines Agency	<b>PAG</b>	Physical Activity Grant
<b>ePAG</b>	European Patient Advocacy Group	<b>PEF</b>	Patient Education Fund
<b>EPF</b>	European Patients' Forum	<b>PPR</b>	Public Policy Review
<b>ERIN</b>	European Rare and Inhibitor Network	<b>RFT</b>	Replacement Factor Therapies
<b>ERN-EuroBloodNet</b>	European Reference Network for Haematological Disorders	<b>SC</b>	Steering Committee
<b>EU</b>	European Union	<b>TRANSFORM</b>	European Alliance for Transformative Therapies
<b>EUHASS</b>	European Haemophilia Safety Surveillance	<b>UK</b>	United Kingdom
<b>EUPATI</b>	European Patients' Academy on Therapeutic Innovation	<b>VWD</b>	von Willebrand Disease
<b>EURORDIS</b>	EURORDIS-Rare Diseases Europe	<b>WBD</b>	Women and Bleeding Disorders
<b>GA</b>	General Assembly	<b>WFH</b>	World Federation of Hemophilia
<b>GT</b>	Glanzmann Thrombasthenia	<b>WG</b>	Working Group
<b>HCP</b>	Healthcare Professional	<b>WHO</b>	World Health Organisation
<b>HTA</b>	Health Technology Assessment	<b>YFP</b>	Youth Fellowship Programme
<b>ISTH</b>	International Society on Thrombosis and Haemostasis		

# Message from the EHC President

Dear members of the European Haemophilia Consortium (EHC),

Reflecting on 2025, this has been a year of **consolidation** and careful refinement for our organisation. Building on the strategic direction set in previous years, we focused on strengthening the foundations of our work, ensuring that the EHC continues to operate with stability, clarity, and purpose. The consolidation of the Steering Committee (SC) has been a key achievement, alongside a series of targeted adjustments aimed at improving our functional efficiency and long-term sustainability.



At the same time, we have continued to evolve as a community. A key priority this year has been embracing and reflecting the **growing diversity** within the bleeding disorders community. The EHC is committed to being inclusive and empathetic towards all individuals living with haemophilia and other bleeding disorders. This broader, more inclusive approach is not only necessary but also a sign of a modern and forward-looking organisation.

This year has also been marked by significant financial challenges across Europe and beyond. Despite this, we have made a determined effort to preserve our core activities and events. We firmly believe that maintaining opportunities for connection, education, and advocacy is essential — because our community must always come first.

I would like to extend my sincere and heartfelt **thanks to the EHC Staff** for their professionalism, dedication, and resilience throughout the year. Their work behind the scenes is vital to everything we achieve. I also wish to **thank all our Committees**, including the SC, whose commitment and guidance have been instrumental during this period of consolidation.

Finally, I would like to express **deep gratitude to all members of our community** — particularly the many volunteers who, day after day, dedicate their time and energy to advancing our shared mission. Their commitment, often in challenging circumstances, is truly inspiring and remains the driving force behind the EHC.

Together, we will continue to build a stronger, more inclusive, and resilient EHC, committed to ensuring equitable access to care and support for all.

**Miguel Crato**  
EHC President

Our three strategic pillars — Education, Communication, and Advocacy — have continued to guide all our activities. They remain essential in ensuring that we provide meaningful support to our **National Member Organisations (NMOs)**, empower our community with knowledge, and advocate effectively at both national and European levels.

Throughout 2025, we have maintained a strong emphasis on supporting NMOs, recognising that their work on the ground is central to improving the lives of people with bleeding disorders across Europe.

# About The EHC

**49**

**national patient organisations**

**120,000**

**patients**

The EHC is an international non-profit organisation that represents **49 national patient organisations for people with rare bleeding disorders** located in the World Health Organization (WHO) European region, including 27 Member States of the European Union (EU) and most Member States of the Council of Europe.

The EHC represents **approximately 120,000 people diagnosed** with rare bleeding conditions such as haemophilia, von Willebrand Disease (VWD), and other extremely rare bleeding disorders across Europe. However, experts estimate that many more live with an undiagnosed rare bleeding disorder.

The EHC actively supports its NMOs at national and European levels and helps them engage with each other. The EHC draws on the knowledge of patients, healthcare professionals, the scientific community, European institutions, and the pharmaceutical industry to share expertise within Europe. Also, the EHC collaborates closely with other European patient organisations to ensure a strong collective voice for people with rare bleeding disorders.



## Our objectives:

- Advocating for improving the quality of life of people with rare bleeding disorders
- Monitoring and influencing the development of health policy in Europe
- Advocating for improving diagnosis and treatment
- Empowering EHC NMOs to better advocate for patients in their country
- Ensuring access to safe and efficacious medicines and care
- Promoting research in all areas related to haemophilia and other bleeding disorders
- Promoting patients' rights
- Collaborating with stakeholders to improve care

## EHC Steering Committee

The EHC is governed by a **General Assembly (GA)** composed of representatives from all NMOs. Between general assemblies, the EHC's activities are overseen by a SC elected by the GA and composed of the President, Vice-President, Treasurer, and Steering Committee members.

The SC is elected by the GA for a **four-year term**. SC members fulfill their mandate purely as **non-paid volunteers** in the best interest of the patient community they represent and serve. They usually receive no financial gains or compensation for their time and report annually on any private interests they might have.

In 2025, the SC was composed of:



**Miguel Crato**  
President  
Portuguese NMO



**Tatjana Marković**  
Vice President  
Serbian NMO  
(4-year term until 2028)



**Laura Quintas Lorenzo**  
Treasurer  
Spanish NMO  
(2-year term until 2026)



**Panagiotis Christoforou**  
SC Member  
Greek NMO  
(5-year term until 2029)



**William McKeown**  
SC Member  
United Kingdom (UK) NMO  
(5-year term until 2029)



**Augustas Nedzinskas**  
SC Member  
Lithuanian NMO  
(4-year term until 2028)



**Jamie O'Hara**  
SC Member  
UK NMO  
(October 2024 - October 2025)



**Amy Owen-Wyrd**  
SC Member  
UK NMO  
(October 2024 - July 2025)



**Marius Tanase**  
Co-opted Member  
Romanian NMO  
(4-year term until 2028)



**Brina Zaman**  
Co-opted Member  
Slovenian NMO  
(3-year term until 2028)



**Samuel Compagnin**  
Co-opted Member  
Italian NMO  
(4-year term until 2029)



**Olivia Romero Lux**  
Ex-officio Member  
CEO



## EHC Financial Guidelines

The purpose of the Financial Guidelines is to ensure a smooth functioning of the EHC. These guidelines should be seen as the overall policy to be followed for all financial procedures within the organisation.

The main objectives of the guidelines are:

- to **successfully monitor** the budgets and consequently, the finances of the EHC;
- to **comply with the rules and regulations** of the Belgian accounting standards;
- to ensure more **transparency and accuracy**.

# 03 Staff

Throughout 2025, the EHC team maintained full operational continuity. A long-anticipated milestone was also reached with the successful **launch of the Youth Fellowship Programme (YFP)** — see [page 34](#) for more information.

In May 2025, Project Assistant **Stavroula Koukouzeli** concluded her six-month internship at the EHC.

Later that year, the internship programme underwent an important evolution: it was integrated into the YFP and opened exclusively to members of EHC NMOs.

In October 2025, **Enea Atroce** joined as the first intern under this new model, undertaking a six-month placement under the supervision of **Zita Gacser**.



# Membership



In 2025, the EHC welcomed the Kazakh NMO as its 49th member, marking a continued expansion of its network.

As of that year, the EHC membership comprised the following organisations:

<b>Albania</b>	Shoqatës Shqiptare të Hemofilikëve	<b>France</b>	Association Française des Hémophiles (AFH)
<b>Armenia</b>	Armenian Association of Patients with Hemophilia and Thrombophilia	<b>Georgia</b>	Georgian Association of Hemophilia and Donorship (GAHD)
<b>Austria</b>	Österreichische Hämophilie Gesellschaft (ÖHG)	<b>Germany</b>	Deutsche Hämophiliegesellschaft
<b>Azerbaijan</b>	Hemofiliyalı Xəstələrin Respublika Assosiasiyası	<b>Greece</b>	Σύλλογος Προστασίας Ελλήνων Αιμορροφιλικών (ΣΠΕΑ)
<b>Belarus</b>	Белорусская Ассоциация Больных Гемофилией	<b>Hungary</b>	Magyar Hemofília Egyesület
<b>Belgium</b>	Association de l'hémophilie, von Willebrand et autres pathologies de la coagulation / Vereniging van hemofilie-, von Willebrandpatiënten en andere Stollingsstoornissen (AHVH)	<b>Iceland</b>	Blæðarafélag Íslands
<b>Bosnia and Herzegovina</b>	Udruženje hemofiličara Bosne i Hercegovine	<b>Ireland</b>	Irish Haemophilia Society
<b>Bulgaria</b>	Българска Асоциация по Хемофилия	<b>Israel</b>	עלה – עמותה לחולי המופיליה
<b>Croatia</b>	Društvo hemofiličara Hrvatske	<b>Italy</b>	Federazione delle Associazioni Emofilici (FedEmo)
<b>Cyprus</b>	Παγκύπρια Οργάνωση Αιμορροφιλικών (Π.Ο.Α.)	<b>Kazakhstan</b>	«Қазақстан гемофилиямен ауыратын мүгедектер қауымдастығы» қоғамдық бірлестігі
<b>Czechia</b>	Český svaz hemofiliků	<b>Kyrgyzstan</b>	Общество инвалидов-больных гемофилией Кыргызской Республики
<b>Denmark</b>	Danmarks Bløderforening	<b>Latvia</b>	Latvijas Hemofilijas Biedrība
<b>Estonia</b>	Eesti Hemofiiliaühing	<b>Lithuania</b>	Lietuvos Žmonių Sergančių Hemofilija Asociacija
<b>Finland</b>	Verenvuotosairaudet ry	<b>Luxembourg</b>	Association Luxembourgeoise des Hémophiles

<b>Malta</b>	Malta Bleeding Disorders Society (MBDS)	<b>Slovakia</b>	Slovenské hemofilické združenie
<b>Moldova</b>	Асоціація Гемофілії Молдовы	<b>Slovenia</b>	Društvo hemofilikov in drugih z motnjami strjevanja krvi Slovenije
<b>Montenegro</b>	Crnogorsko društvo za hemofiliju	<b>Spain</b>	Federación Española de Hemofilia (FEDHEMO)
<b>Netherlands, the</b>	NVHP voor iedereen met een erfelijke stollingsstoornis (NVHP)	<b>Sweden</b>	Förbundet Blödarsjuka i Sverige
<b>North Macedonia</b>	Здружение на лица со хемофилија, фон Вилебранд и ретки коагулопатии - Хемолог	<b>Switzerland</b>	Schweizerische Hämophilie Gesellschaft (SHG) / Association Suisse des Hémophiles (ASH)
<b>Norway</b>	Foreningen for blødere i Norge (FBIN)	<b>Tajikistan</b>	Общественная организация «Гемофилия» Республики Таджикистан
<b>Poland</b>	Polskie Stowarzyszenie Chorych na Hemofilię	<b>Türkiye</b>	Türkiye Hemofili Derneği (THD)
<b>Portugal</b>	Associação Portuguesa de Hemofilia e de outras Coagulopatias Congénitas (APH)	<b>Ukraine</b>	Всеукраїнське товариство Гемофілії
<b>Romania</b>	Asociația Română de Hemofilie (ARH)	<b>United Kingdom, the</b>	The Haemophilia Society
<b>Russia</b>	Всероссийское общество гемофилии	<b>Uzbekistan</b>	Узбекское общество гемофилии
<b>Serbia</b>	Udruženje hemofiličara Srbije		

## Grants

As of 2024, the **EHC integrated Activity Grants (AGs)** and **Physical Activity Grants (PAGs)** into the **Patient Education Fund (PEF)** — see [page 35](#) for more information. These grants support NMOs in initiating or sustaining projects that improve the quality of life of people with rare bleeding disorders.

# 05

# 2024 – 2027 Strategic Plan

The 2024-2027 Strategic Plan is based on the following three pillars:



### Advocacy

- Focus on **NMOs** and **country visits**
- **Inclusivity** and information dissemination
- **External presence**



### Communication

- **Internal communication improvement**
- **External communication enhancement**



### Education

- Focus on **multidisciplinary care**
- **Standards of care** for other bleeding disorders
- Education **follow-up**

# Committees and Working Groups

The EHC bleeding disorders community represents individuals with various rare congenital bleeding disorders across 49 EHC NMOs. Committed to a **multidisciplinary approach**, the EHC addresses the complex challenges faced by people living with these conditions — not only the disease itself, including symptoms, severity, and diagnosis, but also broader, evolving needs across the life course,

from childhood to older age. This includes oral, mental, and physical health, as well as differences in experience and access to care across genders.

To advance its work in key areas, the EHC has established dedicated working groups and committees that lead efforts in selected focus areas.

## Medical Advisory Group (MAG)

The MAG is a **group of experts** providing high-level medical and scientific support to the EHC.

They offer strategic input to the SC and staff, and are consulted on *ad hoc* matters, serving as a valued source of expertise and guidance.

In 2025, the MAG was composed of:

- **Dr Maria Elisa Mancuso** (Chair) | Italy
- **Prof Jan Blatný** | Czechia
- **Prof Ana Boban** | Croatia
- **Dr Christoph Königs** | Germany

## Novel Treatment Review (NTR) Working Group (WG)

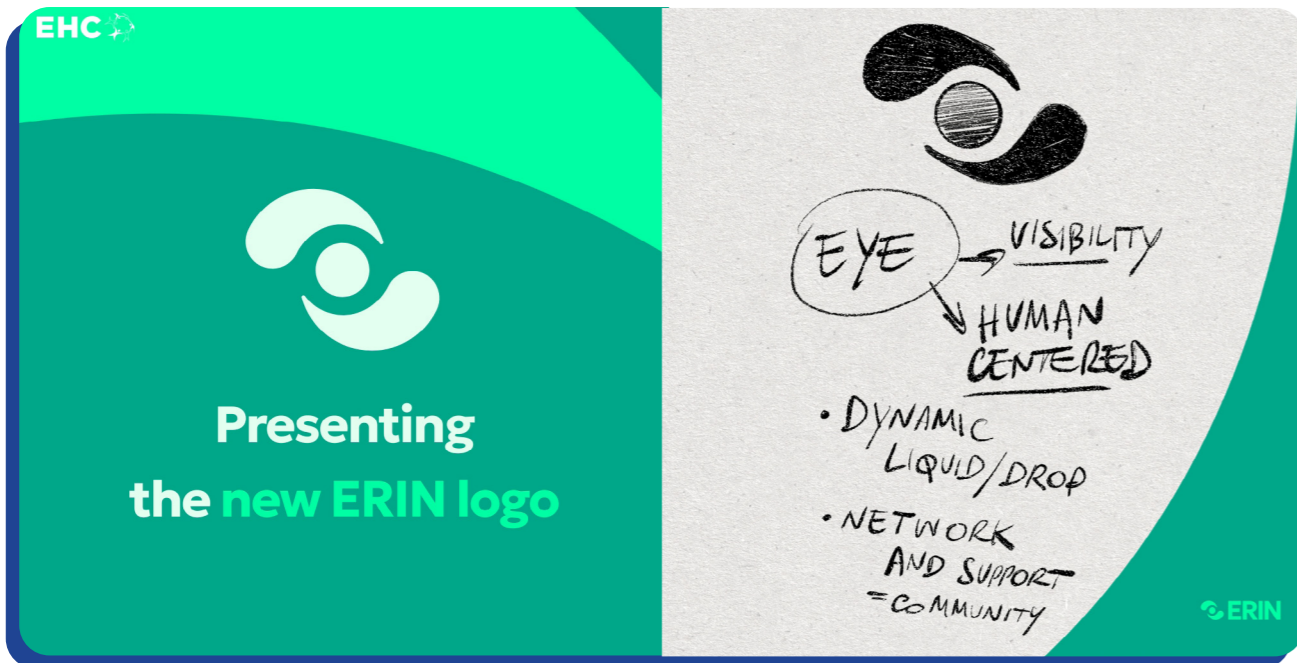
The NTR WG oversees the production of the NTR, a periodic review of novel treatments in haemophilia and other bleeding disorders, by supporting the EHC staff in developing its content. In 2025, the EHC published two NTR editions (find more information on [page 23](#)). The Working Group's work was supported by Roberta Sadauskaite, EHC Public Policy Lead.

In 2025, the NTR WG was composed of:

- **Paul Batty** | University College London | UK
- **Jan Blatný** | University Hospital Brno | Czechia
- **Ana Boban** | University Hospital Centre Zagreb | Croatia
- **Miguel Crato** | EHC President | Portuguese NMO

- **Mariëtte Driessens** | Dutch NMO
- **Radoslaw Kaczmarek** | Polish NMO
- **Ilmar Kruis** | Dutch NMO
- **Maria Elisa Mancuso** | Humanitas Research Hospital | Italy
- **Brian O'Mahony** | Irish NMO
- **David Page** | Canadian Haemophilia Society (until December 2025)
- **Uwe Schlenkrich** | Germany
- **Cédric Hermans** | Saint-Luc University Hospital | Belgium (from October 2025)
- **Gaëtan Dupont** | French NMO (From October 2025)
- **Pratima Chowdary** | Royal Free Hospital | UK (From October 2025)
- **Robert Klamroth** | Vivantes Klinikum im Friedrichshain | Germany (from October 2025)

# European Rare and Inhibitor Network (ERIN) Committee



The ERIN Committee works to understand and prioritise the needs of people with extremely rare bleeding disorders at both community and policy levels, empowering them to lead research that improves treatment and care, and enabling them to actively engage with decision-makers on access to appropriate treatment. The Committee also fosters connections between patients and caregivers for mutual support and education, and provides ongoing support to facilitate knowledge transfer to local communities. It is composed of **people affected by extremely rare bleeding disorders, individuals affected by haemophilia A and B with inhibitors, and multidisciplinary team experts.**

In pursuit of these objectives, the Committee plays an active role in developing and implementing the content and programme of **ERIN**, supporting its promotion, attracting participants to its various

activities, and identifying potential experts to contribute to the programme's content.

In 2025, the Committee continued to raise the visibility of people with extremely rare bleeding disorders through webinars exploring both patient and clinical perspectives on a range of conditions. It also developed content for ERIN-focused sessions at EHC events, assisted in organising the annual **ERIN Summit** (see [page 39](#) for more information), and led the EHC awareness campaign for **Rare Disease Day** (see [page 28](#)). In July 2025, the Committee also marked a milestone for ERIN's identity, with the unveiling of a **new logo and brand identity**. Embodying the programme's core values of empathy, integrity, and inclusion, the new identity reflects ERIN's mission as a voice of hope for an underserved community — a space where stories are shared and needs are heard.



To get in touch with the ERIN Committee: [erin@ehc.eu](mailto:erin@ehc.eu)

To **learn more** about the EHC's work in this focus area, please visit the dedicated page on the **EHC Community website**.

To watch ERIN Webinars, please follow [this link](#).

In 2025, the ERIN Committee was composed of:

- **Maja Søndergaard Knudsen (Chair)** | Danish NMO
- **Enea Atroce** | Swiss NMO
- **Christina Burgess** | UK (until March 2025)
- **Dominik Čepić** | Croatian NMO
- **Miguel Crato** | Portuguese NMO (SC Liaison since July 2025)
- **Maria Elisa Mancuso** | Italy
- **Amy Owen-Wyrd** | UK (SC Liaison until July 2025; Advisor since July 2025)

- **Jim O'Leary** | Irish NMO
- **Jacqueline Cilia** | Maltese NMO (since May 2025)
- **Alison Dougall** | Ireland (since May 2025)
- **Marina Pimentel** | Portuguese NMO (since May 2025)

The Committee's work was supported by **Stefan Radovanovic**, EHC Patient Engagement and Community Lead.

## Mental Health (MH) Working Group

The MH WG was established in March 2025, with a primary focus on developing and implementing a **mental health survey** to assess the needs of the bleeding disorder community. Offered in 19 languages, the survey received 338 responses, with results planned for release in 2026.

In September, the WG also contributed to an **EHC Round Table** with Member of European Parliament (MEP) András Tivadar Kulja, focusing on breaking down stigma and improving access to mental health care (find more information on [page 41](#)).

In 2025, the MH WG was composed of:

- **Scott McLean (Chair)** | UK NMO (until October 2025)
- **Vasileios Kapouranis** (Chair since October 2025) | Greek NMO
- **Shagi Galili** | Israeli NMO
- **Hermanas Usas** | Swiss NMO
- **Tommaso Lembo** | Italian NMO
- **Amy Owen-Wyrd** (SC liaison) | UK NMO (until October 2025)
- **Augustas Nedzinskas** (SC liaison since October 2025) | Lithuanian NMO



The WG's work was supported by **Zita Gacser**, EHC Community and Projects Lead.



To learn more about the EHC's work in this focus area, please visit the dedicated page on the **EHC Community website**.

## Youth Committee

The EHC Youth Committee plays a key role in shaping the strategic direction of youth-focused activities within the EHC. Its remit includes guiding initiatives such as workshops, fellowships, peer support activities, and youth-focused sessions at EHC events. The Committee is also responsible for developing and overseeing the agendas and content of youth training and events, including Youth Leadership Workshops and the Youth Alumni Events, as well as supervising the **EHC YFP** (see [page 34](#) for more information).

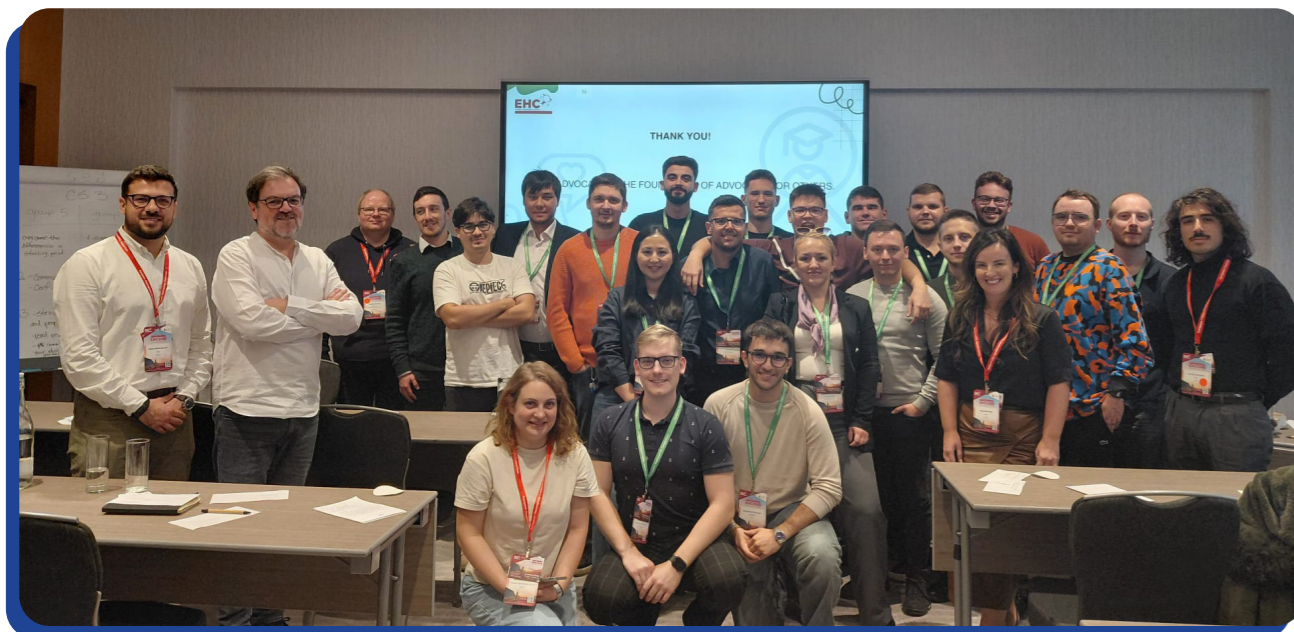
In April, the Committee supported the organisation of the annual **Youth Leadership Workshop** held in Brussels, Belgium, with a programme specifically designed to reflect the interests and needs of young people (see [page 36](#)). In October, the Committee further contributed to the organisation of the third **Youth Alumni Event**, which took place as a pre-EHC Annual Conference activity (see

[page 38](#)). In addition, during the EHC Conference, the Committee hosted its annual **Youth Debate**, offering young members the opportunity to demonstrate their public speaking skills and apply the knowledge and experience gained through the Workshop.

In 2025, the Youth Committee was composed of:

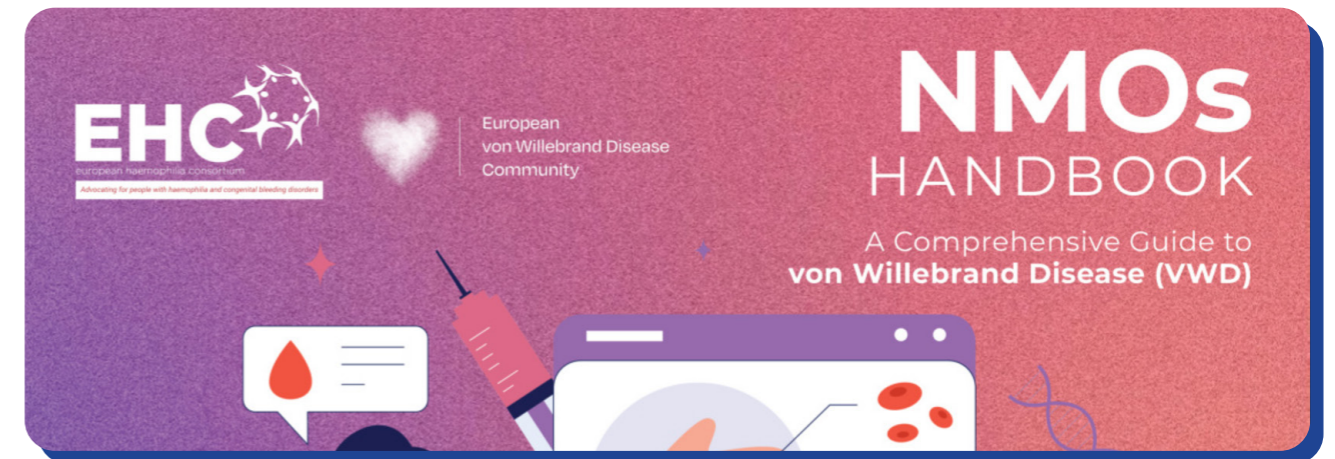
- **Enea Atroce** | Swiss NMO
- **Lorenzo Ghirardi** | Italian NMO
- **Zsófia Keszthelyi** | Hungarian NMO
- **William McKeown** | SC Liaison (since October 2024)
- **Aleksandra Ilijin** | Serbian NMO | EHC Youth Advisor (since February 2025)

The Committee's work was supported by **Stefan Radovanovic**, EHC Patient Engagement and Community Lead.



To **learn more** about the EHC's work in this focus area, please visit the dedicated page on the **EHC Community website**.

## Von Willebrand Disease Committee



In 2025, the VWD Committee continued its work to strengthen the European VWD community through the **#VWDunited initiative**. The Committee remained focused on three agreed priority areas: awareness, engagement, and education and research. It also took the lead in organising the EHC awareness campaign for **European VWD Awareness Day** (find more information on [page 28](#)).

In September, the Committee published a children's book titled **Emma and the Playhouse**, written by Committee Member Cathy Verbraeken and illustrated by Mariana Ostanik. The book serves a dual purpose: supporting children with VWD in sharing their experiences, while helping children without the condition develop understanding and compassion for their peers.

From 20 to 21 September, the first-ever **VWD Summit** was held in Riga, Latvia. Over two days, the programme covered scientific and clinical updates, treatment advances, patient care, and the challenges of living with VWD across different life stages. A panel discussion and roundtable brought together advocacy leaders and experts to address

policy and engagement strategies. Find more information on [page 37](#).

Finally, the Committee produced the **NMO Handbook: A Comprehensive Guide to von Willebrand Disease (VWD)**, designed to support national member organisations, patients, and other interested readers with a clear overview and practical guidance.

In 2025, the VWD Committee was composed of:

- **Julia Rauscher** (Co-chair) | Austrian NMO
- **Joanne Traunter** (Co-chair) | UK NMO
- **Lena Steinbrecher** | German NMO (since March 2025)
- **Başak Koç Şenol** | Turkish NMO
- **Cathy Verbraeken** | Dutch NMO
- **Baiba Ziemele** | Latvian NMO (until October 2025)
- **Laura Quintas Lorenzo** (SC Liaison) | Spanish NMO

The Committee's work was supported by **Zita Gacser**, EHC Community and Projects Lead.



To get in touch with the EHC VWD Committee: [vwd@ehc.eu](mailto:vwd@ehc.eu)

Reach out to us if you want to join our WhatsApp support group (open to VWD patients only!).

To learn more about the EHC's work in this focus area, please visit the dedicated page on the **EHC Community website**.

## Women and Bleeding Disorders (WBD) Committee



The WBD Committee works to improve the quality of life for women and girls affected by bleeding disorders. At the European level, it focuses on raising awareness, recognition, support, and education within the bleeding disorder community. The Committee also organises the EHC awareness campaign for **International Women's Day** (find more information on [page 29](#)).

In 2025, the Committee launched a **survey** for women and girls with bleeding disorders and their caregivers, offered in 12 languages. The survey received nearly 400 responses, with results planned for release in 2026.

In March, the Committee contributed to an **EHC Round Table** with MEP Stine Bosse, focusing on advancing women's health (see [page 40](#)). The Committee's engagement continued at the **EHC Leadership Conference** in June in Brussels, Belgium, where Committee members supported leadership development across the community. In October, they led a session on women's health and related barriers at the **EHC Annual Conference** in Vienna, Austria.

In 2025, the WBD Committee was composed of:

- **Anna Tollwé (Chair)** | Swedish NMO
- **Marion Bräuer** | Austrian NMO
- **Yannick Collé** | French NMO
- **Aleksandra Ilijin** | Serbian NMO (since February 2025)
- **Ana Cristina Monteiro Pastor** | Portuguese NMO
- **Bernadetta Pieczynska** | Polish NMO
- **Brina Zaman** | Slovenian NMO
- **Tatjana Marković (SC Liaison)** | Serbian NMO

The Committee's work was supported by **Zita Gacser**, EHC Community and Projects Lead.

*As 2025 marked the end of the Committee's three-year term, we would like to sincerely thank all Committee members for their dedication and invaluable contribution to the bleeding disorders community.*



To learn more about the EHC's work in this focus area, please visit the dedicated page on the **EHC Community website**.

# 06

## 2025 Activities

### Advocacy

#### Novel Treatment Review (NTR)

The NTR is a **periodic review of novel treatments** in haemophilia and other bleeding disorders entirely developed by the EHC to help educate its NMOs about the rapidly changing landscape of medicinal treatment in rare bleeding disorders.

The review covers recent major developments and is divided by different types of disorders for which there is an update to report. The information provided in this publication is compiled from multiple sources, including presentations at recent scientific meetings, websites, financial information, and writing directly to pharmaceutical companies. It is then redrafted and presented in easy-to-understand language.

This review is updated twice a year. The EHC encourages its NMOs to use and adapt this

document to their national needs, but does not bear responsibility for any modifications made to its content.

This document is overseen by the EHC NTR WG and edited by both NTR WG volunteers and selected members of the EHC MAG.

**In 2025, the EHC published two editions.**



All **NTR issues** are available on the **EHC Academy**.

#### Public Policy Review (PPR)

The PPR of **EU legislation** is developed entirely by the EHC to inform its NMOs about health policy and legislative developments that directly impact the bleeding disorders community.

Initially shared as a quarterly policy review, it has now been transformed into a periodic report available on the EHC Academy.

**In January 2025, the EHC published a PPR covering legislative initiatives from the second half of 2024.**



All **PPR issues** are available on the **EHC Academy**.

## Round Tables

The EHC hosts a series of Round Tables that bring together stakeholders in the field of congenital bleeding disorders around one table. The main objective is to provide a neutral forum for constructive and open education, discussion, and exchange on central issues. In addition to industry

and patient stakeholders, the Round Tables target key European policy and decision-makers.

In 2025, the EHC organised **two Round Tables**, one in March and another in September. Find more information on [page 40](#).



## Think Tank

Launched in 2021, the EHC Think Tank served as a platform for driving healthcare system change by identifying key areas for transformation and addressing complex issues through broad, multi-stakeholder collaboration. Over its lifespan, it made significant strides in shaping the future of healthcare in Europe across five thematic workstreams: Registries, Hub and Spoke Model, Patient Agency, Access Equity, and Future Care Pathways.

In 2025, the Think Tank **concluded its work** with the publication of the final output from the

Registries workstream, bringing its activities to a close. The insights and outcomes generated across all workstreams continue to inform the EHC's advocacy work, through engagement with decision-makers at EU and Council of Europe institutions, as well as at the national level through EHC national member organisations.

*We extend our sincere appreciation to all workstream members for their dedication, expertise, and collaborative spirit throughout the EHC Think Tank's four years of work.*

## Collaborations and Partnerships

The advocacy and awareness-raising work of the EHC would not be possible without the various partnerships and collaborations pursued.

### Critical Medicines Alliance (CMA)



### European Alliance for Transformative Therapies (TRANSFORM)



### European Association for Haemophilia and Allied Disorders (EAHAD)



### European Association for the Study of the Liver (EASL)



### European Dental Hygienist Federation (EDHF)



### European Hematology Association (EHA)



### European Haemophilia Safety Surveillance (EUHASS)



### European Patients' Academy on Therapeutic Innovation (EUPATI)



### European Patients' Forum (EPF)



### EURORDIS-Rare Diseases Europe



### European Reference Network for Rare Hematological Diseases (ERN-EuroBloodNet)



### International Society on Thrombosis and Haemostasis (ISTH)



### Platform of Plasma Protein Users (PLUS)



### World Federation of Hemophilia (WFH)



In 2025, EHC volunteers and staff actively contributed to a wide range of partner organisations, while also expanding the EHC's collaborative network to new partners such as EUPATI and EDHF.

As member of the **EAHAD Gene Therapy WG**, EHC President Miguel Crato attended six meetings throughout the year. The Working Group made tangible progress on two fronts: a lexicon article on gene therapy was submitted for publication to Research and Practice in Thrombosis and Haemostasis, while a survey paper exploring knowledge and perspectives on gene therapy was drafted and had entered the author review process by year end.



Amy Owen-Wyrd represented the EHC in the **EAHAD Glanzmann Thrombasthenia (GT) WG**, attending six meetings over the course of the year. The Working Group's agenda was broad, spanning a preconception survey developed in collaboration with the Women and Girls+ with Bleeding Disorders Working Group, a Light Transmission Aggregometry monitoring project, and a dedicated focus on GT and pregnancy considerations. Work also progressed on a position paper on platelet transfusion in GT, with all of these efforts oriented towards promoting more standardised care pathways across Europe.

Maja Søndergaard Knudsen represented the EHC in the **EAHAD Very Rare Coagulation Factor Deficiencies WG**, which convened four times in 2025. The year proved productive: eLearning modules were developed, and two surveys — one targeting patients and one aimed at healthcare professionals — were completed and closed. The Working Group also published an opinion paper

on heavy menstrual bleeding, and by year end had taken the first steps towards a joint translational call application with the European Rare Disease Research Alliance.

Laura Quintas Lorenzo attended the founding meeting of the newly established **EAHAD VWD WG** in November, where short-, medium- and long-term projects were discussed and a survey was set in preparation. She also continued her representation in the **EAHAD Women and Girls+ with Bleeding Disorders Working Group**, attending three meetings — two online and one in person at the EAHAD Congress. Topics included the upcoming joint guideline project with ISTH and the International Federation of Gynecology and Obstetrics, congress poster presentations, a menstrual outcomes paper, and follow-up on the EHC patient survey. A poster was presented at both the EAHAD and ISTH congresses, and the Let's Talk About Periods annual report was published in several languages.

Daniel-Aníbal García Diego represented the **EHC at the EHA Patient Advocacy Committee**, with William McKeown serving as alternate. Over the course of the year, the Committee held four plenary meetings, complemented by ad hoc consultations. Much of the work centred on ensuring that the patient perspective was reflected in EHA Clinical Practice Guidelines, particularly on VWD and inherited platelet disorders, as well as in the scientific programme of the EHA Annual Congress. The Committee also provided input into two EMA consultations: the International Council for Harmonisation's E22 Guideline on Patient Preference Studies and the EMA Reflection Paper on Patient Experience Data. The year brought notable outcomes for EHC representation in guideline development: Laura Quintas Lorenzo and Cathy Verbraeken were put forward for the EHA guideline on VWD, while Marina Pimentel was nominated as EHC patient representative on the joint EHA-ISTH guideline on inherited platelet disorders.

Gaëtan Duport and Roberta Sadauskaite continued to represent the EHC at the **European Commission's Health Technology Assessment (HTA) Stakeholder Network**, attending seven meetings over the course of the year. These ranged from plenary sessions in Brussels and working group meetings on patient identification and HTA Regulation evaluation, to a two-day training in Austria and a meeting at the European Access Academy. Throughout, the EHC advocated for rare bleeding disorder-specific approaches in joint clinical assessments and contributed to the early evaluation of the EU HTA Regulation's implementation. The EHC's engagement with this process also fed into its own capacity-building

efforts, with a dedicated training session on EU HTA processes delivered at the EHC Leadership Conference.

In 2025, EHC was also elected as member of the **EMA Patients' and Consumers' Working Party**, with the inaugural meeting held in September. During the year, EHC representatives attended two meetings, contributing on various discussions such as medicine shortages, assessment of medicines in the EU and new EU Pharmaceutical Legislation.

William McKeown represented the EHC at **EUHASS**, attending two meetings — one in person in Milan in February and one virtual in September. Discussions ranged across a broad set of topics, including governance, reporting, EMA/Food and Drug Administration strategy, data quality, and clinical events such as thrombosis, gene therapy, and Bleeding Disorders of Unknown Cause. The year also brought a number of concrete advances: pharmacovigilance reporting was streamlined through PowerBI, national registry integration was piloted, and work began on developing patient-facing information. Publications on thrombosis, intracranial bleeding, and malignancies post gene therapy are also in the pipeline.

Marius Tanase continued to represent the EHC in the **ERN-EuroBloodNet European Patient Advocacy Group (ePAG)**, attending four meetings over the course of the year, including one in person at the EHA Congress in Milan, Italy, which proved a valuable opportunity for connection and joint work. The agenda focused on welcoming two new ePAG members, finalising the Terms of Reference, and preparing for the High-Level Meeting on a European Innovation and Care Ecosystem for Rare and Complex Diseases. This three-day event, which brought together key stakeholders from across the rare disease community, resulted in the launch of the Declaration on the European Innovation and Care Ecosystem for Rare and Complex Diseases, setting out a shared vision, strategic priorities, and a roadmap for action to revitalise the innovation and

care ecosystem across the EU.

EHC also maintained its long-standing partnerships with the **WFH**, where Miguel Crato and Panagiotis Christoforou represented the EHC on the **Coagulation Products Safety, Supply and Access Committee** and the **Medical Advisory Board** respectively. The EHC also collaborated with **ISTH** on Annual Bleed Rate methodology and on Mild and Moderate Haemophilia.

The EHC, represented by Roberta Sadauskaite, continued its collaboration with the **PLUS group**, notably by monitoring legislation related to blood and plasma donation, as well as the supply and shortages of treatments for the bleeding disorders community.



The EHC's engagement with **EPF** was characterised throughout 2025 by strategic information sharing and mutual social media support. On World Haemophilia Day, EHC CEO Olivia Romero Lux joined the EPF Podcast to advocate for women with bleeding disorders.

On 20 November, Olivia Romero Lux also represented the EHC at the **TRANSFORM Alliance** event *Igniting Innovation: The Future of the EU ATMP Ecosystem* at the EP, where she presented the patient perspective on access to advanced therapies.

## New partnerships

In June 2025, the EHC signed a partnership with **EUPATI**, a non-profit foundation providing patients and the public with accessible education on the lifecycle of medicines research and development, while upskilling professionals on meaningful patient involvement. The partnership aims to strengthen patient education, advocacy, and engagement across Europe.

As part of a continued effort to ensure a multidisciplinary approach to care, the EHC also established a collaboration with **EDHF** toward the end of 2025, raising awareness among dental hygienists of the specific clinical needs of patients with bleeding disorders.

# Awareness Campaigns

## European VWD Awareness Day

📅 1 February 2025

In 2025, we marked the third European VWD Awareness Day. The theme for the campaign was *Making the Invisible Visible*.

To commemorate the occasion, the EHC VWD Committee released **on the @EHCTVChannel on YouTube** the first 10 videos of its online educational programme, **Topic on Focus: VWD**, developed in partnership with the ERN-EuroBloodnet. The videos feature expert-led webinars covering key aspects of VWD, combining medical insights, personal experiences, and practical strategies to help patients and caregivers navigate daily life.

VWD Committee members also shared their personal experiences and **hopes for the future**, aiming to raise awareness and offer encouragement to those affected by the condition.



To learn more about the campaign, please visit the **EHC website**.

## Rare Disease Day

📅 28 February 2025



Rare Disease Day, commemorated on 29 February in leap years and on 28 February in common years, is the rarest day of the calendar and is dedicated to raising awareness of rare diseases and advocating for improved access to treatment and medical representation. For the EHC community, Rare Disease Day provides an important moment to draw attention to the specific challenges faced by people with extremely rare bleeding disorders, including individuals with haemophilia and inhibitors, as well as their family members. It also serves as an opportunity to broaden the discussion to include communities that are frequently overlooked, particularly those who continue to face delays in receiving an accurate diagnosis, or who remain undiagnosed. To mark Rare Disease Day in 2025, the **EHC ERIN Committee** raised awareness of the challenges

faced by the extremely rare bleeding disorders patient community in accessing timely diagnoses and appropriate treatments. This was achieved through the **dissemination of infographics highlighting** disease prevalence and limited treatment options, alongside the sharing of ERIN members' lived experiences.

As part of this initiative, the ERIN Committee organised a **community-focused closed-door webinar on March 1**, providing a safe and supportive space for community members to openly discuss and identify the most common issues and challenges they face. The outcomes of this discussion informed the development of subsequent open-door webinars, designed to stimulate broader dialogue on individual extremely rare bleeding disorders.



To learn more about the campaign, please visit the **EHC website**.

## International Women's Day

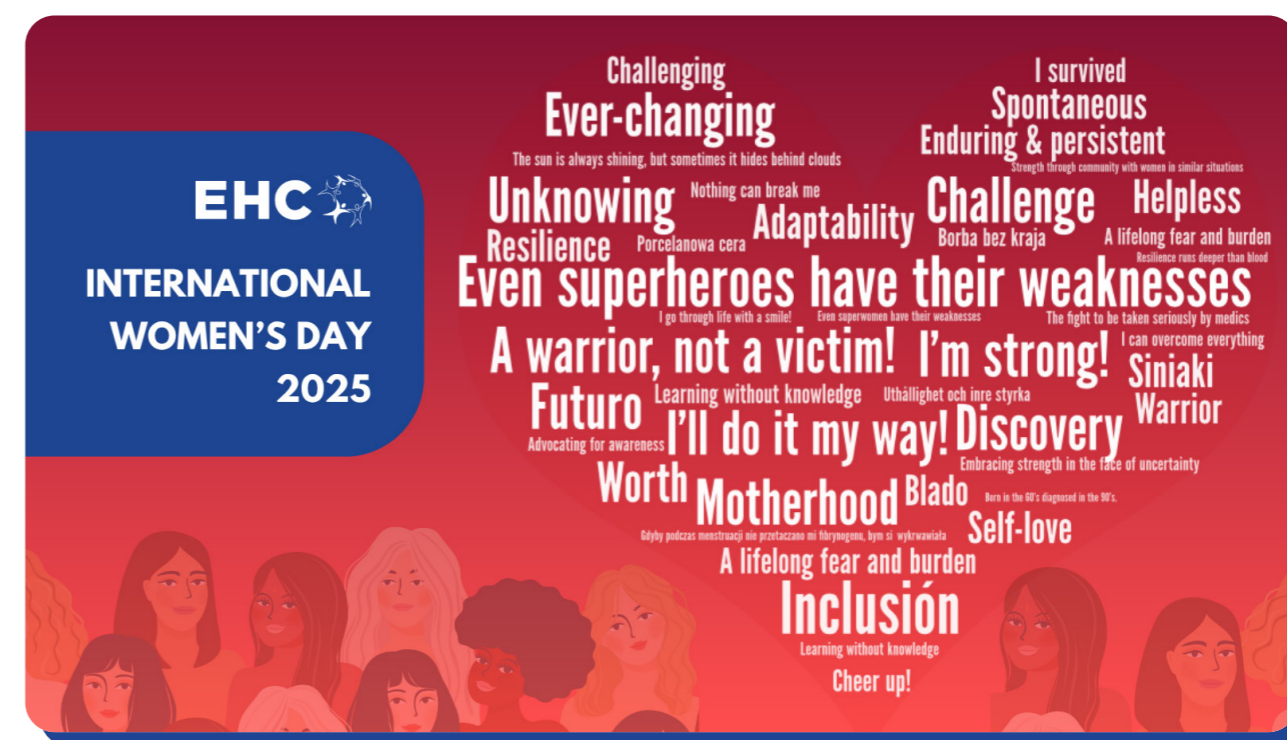
📅 8 March 2025

Each year, the EHC WBD Committee marks International Women's Day with a dedicated awareness campaign. In 2025, the Committee unveiled its **Wall of Words**, a tribute to the stories, struggles, and triumphs of women with bleeding disorders, expressed in multiple languages.

- "Cheer up! The sun is always shining, but sometimes it hides behind clouds."
- "Living as a woman with a bleeding disorder means embracing strength in the face of uncertainty, advocating for awareness, and proving that resilience runs deeper than blood."
- "Gdyby podczas menstruacji nie przetaczano mi

fibrynogenu, bym się wykrwawiała." (Translation: "If I hadn't been transfused with fibrinogen during my menstruation, I would have bled.")

- "Borba bez kraja" (Translation: "A fight without end.")
- "Uthållighet och inre styrka" (Translation: "Perseverance and inner strength.")
- "Strength through community with other women in the same situation."
- "A warrior, not a victim!"
- "Resilience."
- "Adaptability."
- "Discovery."




To learn more about our campaign, please visit the **EHC Community website**.

## World Haemophilia Day

17 April 2025



Every year, on April 17, the bleeding disorders community worldwide marks World Haemophilia Day to raise awareness about all bleeding disorders and advocate for better access to treatment and care.

In 2025, the EHC turned its focus to **women and girls with haemophilia and female haemophilia carriers** — a group that has long faced significant healthcare barriers, including lack of recognition, delayed diagnoses, and limited access to care. Long perceived as “just carriers,” women who inherit haemophilia genes frequently experience significant bleeding and low factor levels. Yet their symptoms are often overlooked, do not always correlate with factor levels, and tend to manifest differently than in males, most notably through heavy menstrual bleeding and emotional distress that can affect their quality of life.

While recent changes to diagnostic criteria now allow for the diagnosis of haemophilia in females

with low factor levels and distinguish between symptomatic and asymptomatic carriers, raising awareness, improving diagnosis, ensuring accurate classification, and expanding access to emerging treatments remain key priorities.

To mark the occasion, the EHC released two new resources:

- **Is haemophilia (fe)male?** — a booklet developed by the EHC exploring the clinical realities, lived experiences, and systemic gaps faced by female carriers and women and girls with haemophilia, available in multiple languages.
- **A podcast episode hosted by the European Patients’ Forum (EPF)**, featuring EHC CEO Olivia Romero Lux, highlighting the importance of recognising and supporting this underserved group.



To learn more about the campaign, please visit the **EHC website**.



Discover all our booklet translations on the **EHC Academy**

## #ThisWay Campaign

Physical activity continues to play a vital role in managing bleeding disorders — strengthening muscles and joints, reducing the risk of bleeds, and enhancing overall quality of life. In 2025, the EHC’s #ThisWay campaign stayed true to its mission of promoting health and well-being through patient stories, physical activity initiatives, and community engagement.

Throughout the year, the EHC highlighted two **powerful patient stories** that offered insight into the diverse experiences of people living with bleeding disorders. These personal accounts aimed to inspire, educate, and empower the community, while emphasising resilience, advocacy, and self-care.

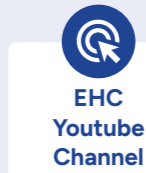
- [Mitja’s story](#) (patient with severe haemophilia A, Slovenia)
- [Gertu’s story](#) (patient with severe haemophilia A, Estonia)

The EHC also launched the **#ThisWay webinar series**, designed to support and inform individuals with bleeding disorders and their caregivers.

In 2025, three webinars were delivered:

- *Storytelling and Awareness* | Camilla Wensing and Enea Atroce
- *Moving Better, Feeling Better: Enhancing Joint Health Through Exercise* | David Stephensen
- *Expressing Emotions Through Art* | Shagi Galili

All webinars were recorded and published on the **@EHCTVChannel on YouTube**, with subtitles available in six languages: English, Spanish, Italian, French, German, and Russian.



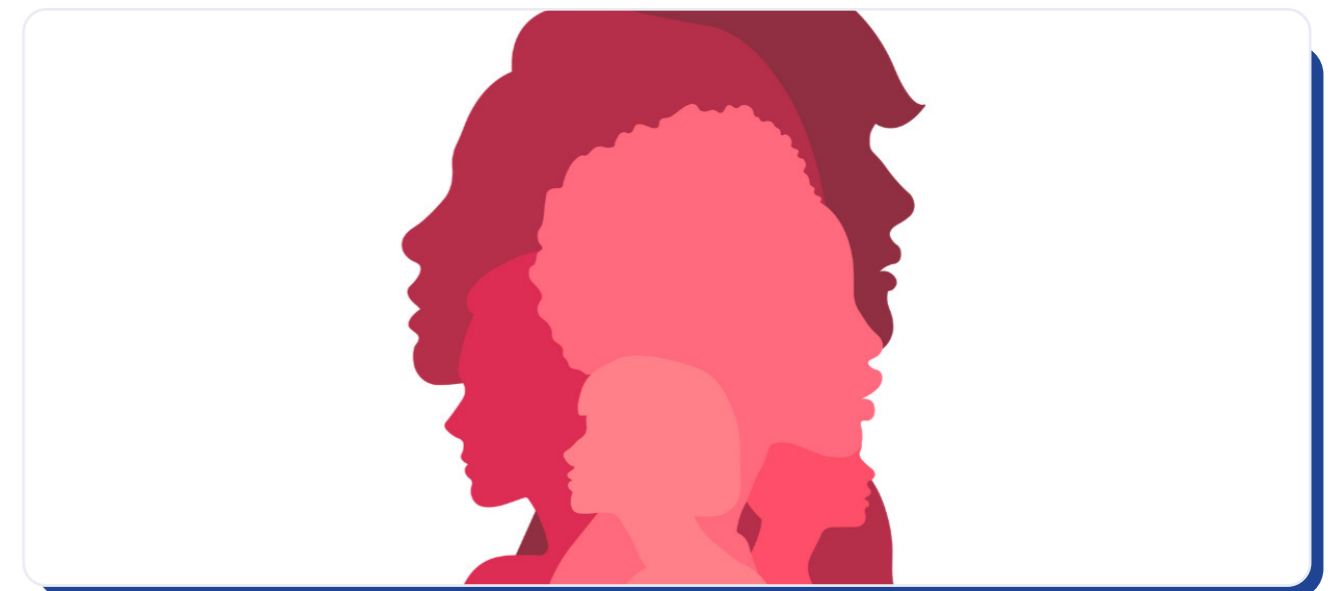
Watch the webinar recordings on the **EHC YouTube Channel**

The campaign also featured two physical activity initiatives that encouraged participants to stay active and prioritise their health. During the EHC Leadership Conference, the **#ThisWay Photo Walk Challenge** was introduced. This light, self-guided walking activity invited participants to explore Brussels together while completing a series of creative tasks.

Later in the year, during the EHC Annual Conference, a **#ThisWay Walk** was organised. This guided activity allowed participants to enjoy a relaxed walk, learn more about the city from local guides, and connect with others after the conference sessions, ahead of the gala dinner.



To learn more about the campaign, please visit the **EHC Community website**.



# Courses and programmes

## Health Economics Course

22 September - 31 October 2025

### 100%

Overall rating of the course  
(60% excellent, 40% very good)

Following two successful years, **the third online edition of the course** was offered in 2025 to continue providing accessible education for patients and patient organisations for engaging in HTA in bleeding disorders.

The course featured **subtitled online educational modules** covering key health economics concepts relevant to bleeding disorders, including HTA, cost-effectiveness, budget impact models, alternative payment approaches, and treatment updates. Each module included review questions, with additional materials provided for further exploration.

### 100% positive

Content evaluation

Participants who passed the final quiz could download a certificate of completion and share it on social media.

Building on excellent feedback from the previous editions, the 2025 version retained its core programme while providing content updates and introducing enhancements on the e-learning platform for a better learning experience. These included a direct opportunity to ask questions to the speakers in the forums and an improved user interaction with the content.

"I would like to thank the EHC for this opportunity to take this course, as it has built my capacity and refreshed my knowledge to support and strengthen the decision-making activities in my NMO."

"I would like to participate in other courses like this in the future."

A poster on **Empowering Patient Advocacy Through Health Economics: Insights from the first two years of the EHC - Health Economics in Europe Course** was co-authored by the EHC, Prime HCD, Brenda Padilla, and presented by Prime HCD at the World Orphan Drug Congress that took place in Amsterdam, the Netherlands, on October 27–29, 2025.

The EHC wishes to thank the Prime HCD team, EHC MAG Chair Maria Elisa Mancuso, and Brenda Padilla for their invaluable input in the content of this course. As we express our gratitude, we also want to acknowledge the efforts of the lecturers who have worked to ensure the success of the course: Jonathan Evans, Enrico Ferri Grazzi, Idaira Rodriguez Santana, and Claudia Mighiu.

## EHC – ERN–EuroBloodNet Topic on Focus: VWD Educational Programme

1 February 2024 - 20 March 2025

The EHC and **ERN-EuroBloodNet** launched the Topic on Focus: **VWD for Patient Organisations and Healthcare Professionals on European VWD Awareness Day 2024** (February 1). The programme ran until 20 March 2025.

This educational initiative was developed in partnership with **EURORDIS** and supported by members of the scientific committee: Prof Sophie Susen (Centre Hospitalier Universitaire de Lille, France), Prof Jeroen Eikenboom (Leiden University Medical Centre, the Netherlands), and Prof Flora Peyvandi (Fondazione Istituto di Ricovero e Cura a

Carattere Scientifico Ca'Granda Ospedale Maggiore Policlinico, Milan, Italy). The programme was also accredited by the **European Board of Accreditation in Haematology**.

This year-long project comprised expert-led webinars addressing crucial topics related to VWD offering valuable insights for both patients and healthcare professionals (HCPs), while shedding light on the challenges faced by those living with this rare disease. These resources are designed for anyone interested in learning more about VWD.



The whole programme recordings are now available to the public on the [@EHCTVChannel](#) on YouTube

## Patient Education Fund



The PEF evolved from the EHC Think Tank, gradually integrating the EHC Organisational Health Programme, grants, country visits, translations of EHC publications, and more educational activities as a multifaceted initiative to enhance knowledge and support for EHC NMOs.

Through country visits, the PEF provides targeted training and fosters collaboration with internal and external stakeholders. Additionally, translation and localisation efforts ensure broader accessibility of EHC publications. Grants enable NMOs to implement specific programmes that improve the quality of life for people with rare bleeding disorders. Furthermore, webinars covering topics such as rare bleeding disorders, ageing, and the EU legislative landscape offer valuable insights to the community.

In 2025, the PEF allowed, for instance, the implementation of many activities in different countries through **through Activity Grants (AGs) and Physical Activity Grants (PAGs)**, and the organisation of an **EHC Country Visit in Slovenia**.

## Country Visits

Beyond advocacy, the EHC Country Visits are an investment in the long-term capacity of EHC NMOs — equipping them with the knowledge, relationships, and confidence to champion patients’ rights long after the EHC delegation has returned home.

### Country Visit in Slovenia

 3-4 November 2025

EHC country visits are a cornerstone of our advocacy work, bringing the patient voice directly to those who shape healthcare policy. The visit to Slovenia illustrated this well.

**Meetings with clinicians** at the Paediatric Clinic and the University Clinical Centre Ljubljana strengthened ties between healthcare professionals and the patient community, while the high-level **roundtable with the Ministry of Health and**

**Social Security** representatives created a united platform to address critical issues such as access to therapies, the role of the National Haemophilia Centre, and the need to ensure more inclusive care for all people living with bleeding disorders.

*The EHC thanks the Slovenian NMO for its warm welcome and remains committed to improving care and quality of life for all patients.*



## Youth Fellowship Programme

The YFP forms part of the youth-focused strategy of the EHC, aimed at fostering cross-border engagement among young community members and strengthening their involvement within the bleeding disorders community. Through the programme, young participants are encouraged to translate theoretical knowledge into practical experience, which they can then apply within their local patient organisations.

As the most recent development within the YFP, the EHC introduced a paid internship opportunity exclusively for members of EHC NMOs. This marks

a significant evolution from the previous internship, which had been open more broadly and was not restricted to community members.

This initiative offers the selected candidate hands-on experience by working closely with EHC staff to support the coordination and implementation of projects designed to improve the quality of life of people living with rare bleeding disorders. In October 2025, Enea Atroce became the first intern to join the team at the Brussels office under this new model, marking a new chapter in the EHC’s youth education and empowerment efforts.

## EHC Grants

Activity Grants (AGs) fund a broad range of initiatives, while Physical Activity Grants (PAGs) focus specifically on activities that strengthen the physical capacity of individuals living with these conditions.

In 2025, the EHC awarded the following AGs and PAGs, providing a total of **€46.250,00 in funding**.



### Activity Grants:

- Switzerland
- Portugal
- Ukraine
- Slovenia
- Malta
- Israel
- Serbia
- Romania

### Physical Activity Grants:

- France
- Ukraine
- Germany
- Lithuania



The AGs supported a range of initiatives, including **national congresses** and annual meetings, **events**, advocacy and access-to-treatment efforts, rehabilitation and summer camps, as well as awareness events and exhibitions around World Haemophilia Day.

Additionally, PAGs funded various activities such as **a sailing trip, a walk in the nature**, sports camps, and an interactive day covering physical activity and nutrition. These initiatives played a key role in strengthening NMO activities and advancing EHC’s mission.

# Events

## Youth Leadership Workshop

📅 4-6 April 2025

The EHC Youth Leadership Workshop has been running for more than a decade. Throughout its history, the programme has focused on the essential elements of effective volunteering, while continuously adapting its content to reflect the evolving priorities and expectations of young participants.

As usual, the Workshop took place in Brussels, Belgium, and welcomed **16 participants representing 13 countries**. The programme was designed around a highly interactive methodology, encouraging engagement through icebreakers, practical group work, case studies, and role-play scenarios.

The sessions were structured around three main thematic areas (modules):

- Fundamentals of patient organisations in the context of volunteering
- The importance of adopting and understanding a strategic process and collaboration, internal and external communications, and medicines development
- Interaction with external stakeholders

Ahead of the workshop, participants contributed information from their respective countries, which was later used to explore and discuss the shared and differing challenges faced by EHC NMOs in delivering care for people with rare bleeding disorders.



"I have come out of the weekend feeling so inspired and informed. Going into the workshop, I had no idea what to expect, but leaving it I wish I could do it all over again!"

- Hannah Byrne, Ireland, 2025 participant

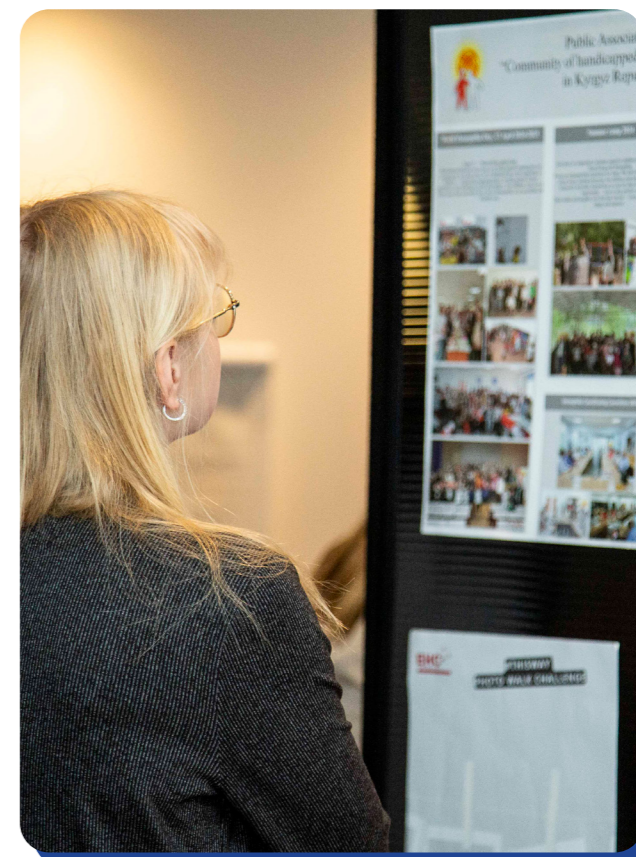
## Leadership Conference

📅 27-29 June 2025

The **11th edition** of the EHC Leadership Conference brought together **79 participants from 30 EHC NMOs** in Brussels, alongside expert speakers, EHC Staff, Steering Committee members, and representatives from sponsoring companies.

As a cornerstone EHC annual event, the Leadership Conference provides a dedicated forum for NMOs to connect, exchange experiences, and discuss shared challenges within the bleeding disorders community. The programme combined expert-led sessions, panel discussions, and interactive breakout activities, with a focus on community development, organisational sustainability, and emerging issues in treatment and care.

Across the three days, participants engaged in clinical and policy discussions, practical workshops on treatment access, and exchanges on national initiatives through poster presentations and networking sessions. Informal moments, such as the **#ThisWay Walk**, also encouraged peer connection and wellbeing. The programme further created space for dialogue with EHC leadership and reflection on future priorities, reinforcing collaboration and shared learning across the network.



## VWD Summit

📅 19-21 September 2025



patients), healthcare professionals, researchers, and EHC Steering Committee members. The diverse participation enabled in-depth discussions and a rich exchange of perspectives on key challenges and opportunities in VWD care.

The programme included sessions on advances in treatment and patient care, the specific challenges of living with VWD, policy and advocacy, collaboration between NMOs, and the future of VWD care and ageing. Participants expressed particular interest in treatment developments, the impact of ageing on care, and strategies to improve patient support and advocacy.

The EHC hosted its **first-ever** VWD Summit in Riga, Latvia, bringing together **44 attendees**, including EHC NMO representatives (primarily VWD

Feedback indicated a very positive experience, with strong enthusiasm for continuing these meetings regularly.

## EHC Annual Conference

3–5 October 2025



The EHC Annual Conference is a key event for the bleeding disorders community, bringing together patients, HCPs, and industry experts to discuss the latest advancements in treatment, research, and patient care. Hosted in Vienna, Austria, by the **Austrian Haemophilia Society**, the 2025 edition welcomed **over 300 attendees**, including EHC NMO

advocates, encouraging knowledge exchange and strengthening community building.

To ensure comprehensive representation, the EHC Conference programme featured expert-led sessions covering a broad range of topics, including haemophilia care in Austria, rare bleeding disorders, VWD, women and girls with bleeding disorders, novel therapies, gene therapy, pain management, mental health, and ageing. Building on positive feedback from the previous year, each session continued to incorporate **both clinician and patient perspectives**, enriching discussions with diverse insights.

On 3 October, the **EHC GA** took place exclusively for NMO members and patient representatives, with 38 NMO representatives in attendance. Russian interpretation was provided.

On 4 October, the WFH held a dedicated session with its NMOs, in alignment with the EHC-WFH Memorandum of Understanding.



## Youth Alumni Event

3 October 2025

part of the EHC Annual Conference

On 3 October, the **EHC Youth Committee** organised a **Youth Alumni Pre-Annual Conference Event** for delegates who had participated in the EHC Youth Leadership Workshops between 2014 and 2024, bringing together alumni from 11 cohorts. Unlike previous editions, the event was held as a pre-conference day, enabling participants to attend the subsequent EHC Annual Conference and further engage with the wider EHC community.

The programme was designed to foster active participation and the exchange of experiences, with discussions focused on representation and sustained engagement. It aimed to empower participants in their roles within patient groups and community initiatives, while also informing the EHC's ongoing reflection on its youth strategy and succession planning across Europe.

## New Technologies Conference

31 October – 2 November 2025



The New Technologies Conference plays a vital role in educating EHC NMOs on the latest advancements in novel therapies through engaging presentations and patient-clinician panel discussions. In 2025, the event brought together **75 participants in Ljubljana, Slovenia**, with priority given to one patient representative and one physician per NMO to ensure broad community representation.

The Conference programme covered replacement and non-replacement therapies, gene therapy, shared decision-making, along with discussions on novel treatments with the EHC MAG. It also addressed the treatment and care of individuals with extremely rare bleeding disorders, as well as those with mild and moderate haemophilia, contributing to a broader understanding and stronger collaboration across the community.

## ERIN Summit

5–7 December 2025

As a key annual event of the **EHC ERIN**, the ERIN Summit provides a safe and inclusive space for people affected by extremely rare bleeding disorders and haemophilia with inhibitors to connect, share experiences, and strengthen peer support, while engaging directly with experts and the wider ERIN community.

The 2025 edition of the ERIN Summit was held in **Berlin, Germany**. The event welcomed **more than 100 participants**, a significant increase compared to previous years, reflecting growing engagement within the extremely rare bleeding disorders community. The programme focused on treatment updates, multidisciplinary care, patient perspectives, and peer support. It also continued to offer a dedicated **Kids' Room** to support family participation.

Across the event, participants engaged in expert-led sessions and practical workshops on topics such as psychosocial support, dental care, and physiotherapy, alongside discussions on treatment experiences and standards of care across countries. Interactive elements encouraged deeper community involvement, while the peer-to-peer



sessions, a longstanding core component of the Summit, provided a confidential space for open exchange and mutual support. The programme also included opportunities for reflection and dialogue on how the EHC can further strengthen its support to the extremely rare bleeding disorders community.

## Round Tables

### Round Table on The Importance of Early Diagnosis for Women with Bleeding Disorders

 25 March 2025

The EHC hosted its first Round Table of 2025, “Advancing Women’s Health – The Importance of Early Diagnosis for Women with Bleeding Disorders”, at the European Parliament in Brussels, Belgium. Co-chaired by **MEP Stine Bosse** (Renew Europe, Denmark), the event brought together 30 stakeholders, including HCPs, patient advocates, and industry representatives, to discuss the importance of early diagnosis for women with bleeding disorders.

The Round Table highlighted major gaps in the diagnosis and care of women with bleeding disorders, particularly due to underrepresentation in research and persistent stereotypes. Discussions focused on delayed diagnosis, the need for multidisciplinary care, and the impact of symptoms across women’s lives.

Participants emphasised improving awareness, training healthcare professionals, and strengthening EU-level policies, research, and collaboration to

ensure earlier diagnosis and more equitable, patient-centred care.

The event concluded with a lively discussion about improving care for women with bleeding disorders. The discussions reinforced **EHC’s commitment to addressing ongoing issues** in the care of women and girls with bleeding disorders and encouraging collaborative efforts to improve access to treatment and patient support for women and girls across Europe.

The EHC also piloted a travel grant initiative to support NMO participation in this type of event.



Executive Summary



Read the Round Table Executive Summary.



### Round Table on Addressing Mental Health in the Bleeding Disorders Community

 23 September 2025



The event brought together 19 participants, representing a diverse group of stakeholders, including EHC NMO representatives, SC members, and staff. Additional contributors included third-party organisations, clinicians, and industry representatives. This wide-ranging participation enabled a meaningful exchange of perspectives on the importance of integrating comprehensive care centres and mental health specialists into treatment plans.



Executive Summary



Read the Round Table Executive Summary.

The EHC held its second Round Table of 2025 on “Beyond the Diagnosis: Addressing Mental Health in the Bleeding Disorders Community” at the Warwick Hotel in Brussels, Belgium, featuring a video message from **MEP András Kulja** (European People’s Party, Hungary).



# Projects

## EHCucate: Advancing Community Education

Since 2021, EHCucate has provided the bleeding disorders community with impartial, tailored education to help navigate an increasingly complex treatment landscape.

### 2024–2025: Transition to the EHC Academy

The recent focus has been the successful migration of EHCucate from a mobile app to a centralised web platform within the EHC Academy. This transition has maximised accessibility for our community members and beyond.

#### Key Achievements in 2025

- **Web Integration:** The project continued to transition to the EHC Academy website, featuring a dedicated information hub and a comprehensive glossary.
- **Topics Expansion:** Originally focused on novel therapies, the scope now encompasses the full therapeutic spectrum, including Replacement Factor Therapies (RFT).
- **New Content Release:** The team has continued the delivery of high-priority modules, ensuring all materials are optimised for the new web interface.

#### New and Updated Topics Moved Online

- History of Haemophilia RFT
- Principles of Factor Replacement
- Practical Foundations of RFT
- Emicizumab Basics



Explore EHCucate online.

By folding EHCucate into the EHC Academy, we have ensured that these vital resources remain a permanent, accessible pillar of education for the European bleeding disorders community.



## Living Well, Ageing Well

### October 2025 - October 2026

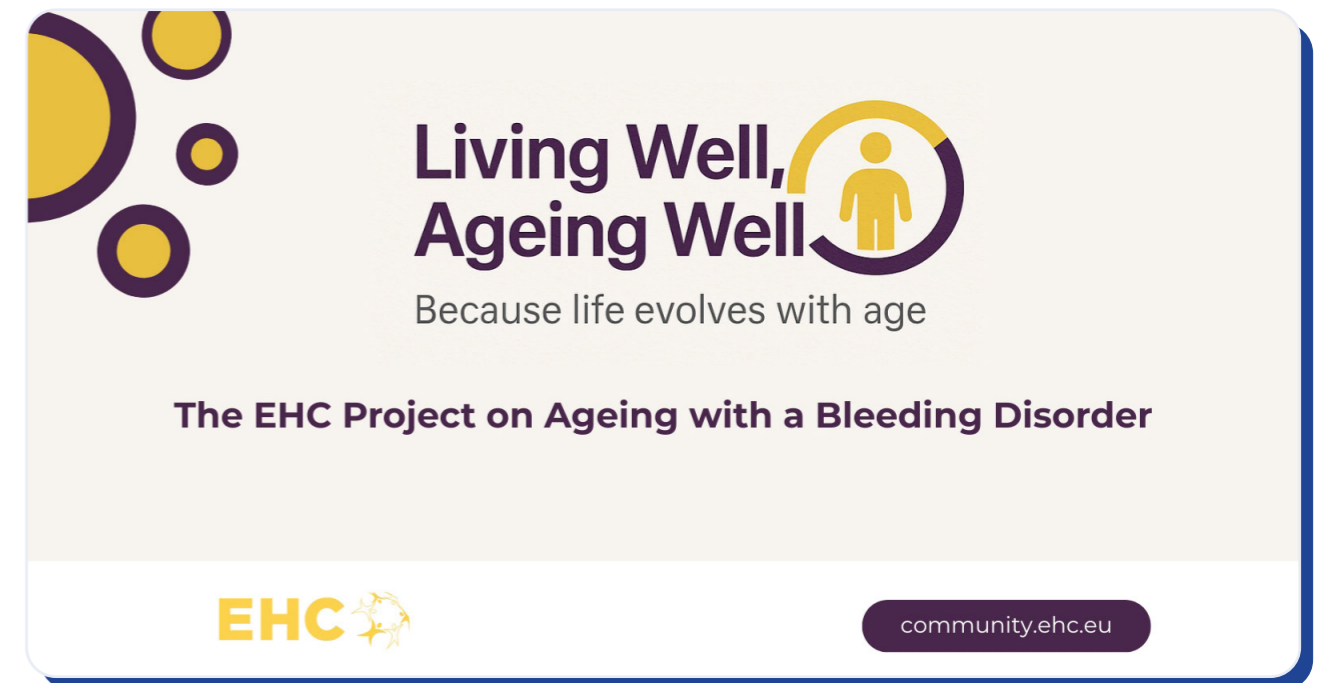
As people with bleeding disorders live longer than ever before, ageing has become an increasingly important focus for the EHC community. In October 2025, the EHC launched Living Well, Ageing Well, a one-year project bringing together experts, patients, and caregivers to explore how to support healthy, active, and fulfilling lives at every stage of ageing for those living with a bleeding disorder.

Through **virtual café talks, peer pioneer podcasts, and webinars**, the project addresses key topics such as nutrition, mobility, frailty prevention, mental well-being, and the lived experiences of older

people with bleeding disorders. Practical resources, including guides and one-pagers, are also developed throughout the programme to empower individuals to take an active role in their health.



To learn more about the project, please visit the **EHC Community website**.



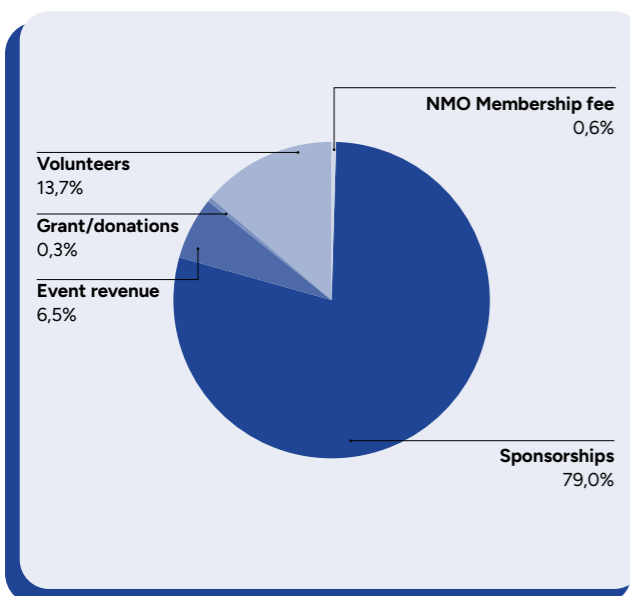
# 2025 Financial Reporting

The financial report aims to demonstrate the EHC's organisational health, and ensure its continued growth and sustainability.

## Independent Auditor's Review Report

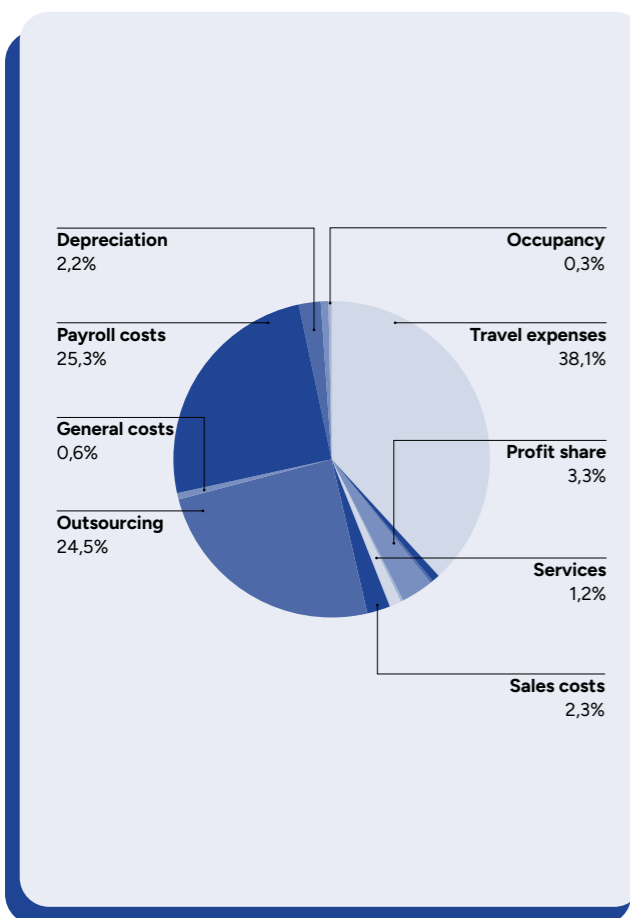


## EHC Income



Income	Finals (€)
NMO Membership Fee	10.900,00
Sponsorships	1.782.900,00
Event(s) revenue	146.555,28
Other Operating Income	1.775,00
Grants/donations	6.530,00
Discount, allowances and rebates	-20.000,00
<b>Turnover</b>	<b>1.928.660,28</b>
Volunteers' Contribution	309.135,00

## EHC Expenditure



Expenditure	Finals (€)
Travel Expenses	832.211,00
Outsourcing	534.858,00
Payroll Costs	553.194,00
Profit Share	72.624,00
Sales Costs	51.152,00
Occupancy	5.538,00
Office Costs	16.488,00
Services	27.069,00
General Costs	13.145,00
Insurances	4.788,00
Marketing	3.705,00
Depreciation	47.718,00
Other operating costs	24.272,00
<b>Total expenditure</b>	<b>2.186.763,00</b>

## EHC Balance Sheet 2025 as of December 2025

### Assets

Fixed assets	Amount	%
Intangible fixed assets	22.252,42	0,9%
Tangible fixed assets	366.927,07	15,6%
Financial fixed assets (cash guarantees)	87,80	0,003%
<b>Total fixed assets</b>	<b>389.267,29</b>	<b>16,5%</b>
Current assets	Amount	%
Amounts receivable within one year	323.251,31	13,7%
Cash at bank and in hand	1.632.661,88	69,3%
Accruals and Deferred Income	11.812,22	0,5%
<b>Total current assets</b>	<b>1.967.725,41</b>	<b>83,5%</b>
<b>Total assets</b>	<b>2.356.992,70</b>	<b>100%</b>

### Liabilities

Liabilities	Amount	%
Equity	1.969.482,96	83,06%
Amounts payable	387.509,74	16,93
<b>Total liabilities</b>	<b>2.356.992,70</b>	<b>100%</b>

# 2025 Corporate Giving Partners

The EHC wishes to acknowledge and thank its 2025 Corporate Giving Partners for making its work possible.

## Elite+ sponsors

Sobi



Novo Nordisk



Roche



## Platinum sponsors

Pfizer



Sanofi



## Gold sponsors

CSL Behring



Regeneron



## Silver sponsors

Biomarin



Hemab



Takeda



Star Therapeutics



LFB



Kedrion



The EHC also wishes to thank the following companies for supporting **individual 2025 projects and events**:

- EHC Conference was supported by CSL Behring, Novo Nordisk, Pfizer, Roche, Sanofi, Sobi and Star Therapeutics
- Patient Education Fund was supported by Regeneron
- Round Tables were supported by CSL Behring, Takeda
- Youth Leadership Workshop was supported by Sanofi and Sobi
- Leadership Conference was supported by Roche, Sanofi, and Sobi
- WHD was supported by CSL Behring and LFB
- VWD Platform was supported by CSL Behring
- WBD Platform was supported Roche
- ERIN Platform was supported by Kedrion, Roche, and Sanofi
- New Technologies Conference was supported by Novo Nordisk
- EHCucate project was supported by Sobi
- Community Advisory Board was held by Pfizer

# 10

## Volunteers

The work of the EHC would not be possible without the support of dozens of volunteers from around Europe who generously offer their time and energy to make the EHC's activities possible.

In 2025, the work of the EHC was supported by a total of 85 volunteers, who all together dedicated 5.152,25 hours of their time to the EHC.

**85**

Total volunteers

**5.152,25**

Volunteer hours



The EHC is immensely grateful to all of you for your energy and dedication!

**Thank you!**

**Everybody** should  
have a voice in  
**decisions about**  
**their care**



We believe lived experiences should shape decisions about care. When people living with haemophilia have a voice in the choices that shape their health, they could live with fewer compromises and greater freedom.



The Apis bull logo is a registered trademark of Novo Nordisk A/S.  
HQ26HRBD00043  
Date of preparation: April 2026

Daniel Jensen, Factor VII deficiency.  
Linda Taylor, Acquired Haemophilia BN.  
Masahiro Umehara, Haemophilia A.  
Pattarakon Poolchai, Haemophilia A.  
Dominic Sánchez, Factor VII deficiency.

We're in relentless pursuit  
of **breakthroughs that**  
**change patients' lives.**

We innovate every day to make the world a healthier place. It was Charles Pfizer's vision at the beginning and it holds true today.

Learn more at [Pfizer.com](https://www.pfizer.com)



# Strategic Patient Community Collaboration Areas until 2030



Sanofi's Commitment to Advancing Hemophilia Care

\*Photos are real people with hemophilia



Working as a committed partner with the hemophilia community, Sanofi is dedicated to advancing hemophilia care by addressing more than just bleeding.

Beyond the Bleed aims to shed light on the full impact of hemophilia and the unmet needs affecting those living with it, their caregivers, and their loved ones.

By focusing on the multifaceted challenges of hemophilia, including mental, emotional, and social impacts, we can develop solutions that best support people living with hemophilia, helping them to live confidently in the present and hopeful for the future.

### WHY IT MATTERS

Hemophilia can affect nearly every aspect of a person's life, but these daily impacts are often overlooked, and current solutions rarely go beyond medical care.

Hemophilia impacts go beyond the bleed and include:

- Relationships
- Physical health
- Mental health
- Careers
- Family planning
- Social interactions
- Travel
- Communication

### OUR APPROACH

Working with the hemophilia community to listen, learn, and ultimately to act, we are:

**LISTENING TO THE COMMUNITY AND BUILDING PARTNERSHIPS:** Working with medical experts, people living with hemophilia, caregivers, advocates, and opinion leaders to better understand lived experiences.

**GATHERING INSIGHTS:** Seeking valuable insights from surveys, advisory boards, and roundtables to understand the full spectrum of hemophilia's effects and what people want from their care.

**SHARING STORIES:** Sharing inspiring stories to raise awareness about the lived experiences of people with hemophilia.

**FOSTERING ADVOCACY & SOLUTIONS:** Fostering advocacy and co-creating solutions that address the broader impacts of hemophilia, aiming to improve overall quality of life.

### COMPREHENSIVE INITIATIVE

Beyond the Bleed encompasses:

- Global Hemophilia Life Stages and Changes Survey
- "Through My Eyes" Patient Video Series
- Professional Advisory Board
- Patient Advisory Board
- Advocacy & Changemakers Events
- Humanitarian Aid

Recognising the **TREATMENT BURDEN** of different patient subpopulations and enabling patients to **CHOOSE** the most appropriate therapy offering, striving towards normalisation



Advancing the **ADVOCACY** impact of patient communities to help extend **ACCESS** to advanced therapies for more people that need prophylaxis based on their phenotype

**UNDERSTANDING** the **NEEDS** of underserved parts of the communities, enabling actionable insights to inform our development strategies, enable patient access, and improve outcomes

Please listen to this podcast



### LEARN MORE

At Sanofi, we're going beyond the bleed to meaningfully advance the hemophilia care paradigm. Learn more at [surl.sanofi.com/beyondthebleed](https://surl.sanofi.com/beyondthebleed).

LIBERATE  
LIFE



## Living with haemophilia with confidence: Where does your journey begin?

Staying engaged in your haemophilia care and seeking regular check-ups to monitor your health can give you the freedom to move and live confidently – allowing you to engage fully in life and pursue your goals, no matter how big or small

Sobi's Liberate Life resources can potentially support your journey towards living confidently with haemophilia. Whether you're looking to engage in a new physical activity, plan a trip or support your child's independence as a carer, you will have all the guidance you need to overcome personal challenges and build your confidence in managing haemophilia

Learn more about living with haemophilia with confidence at [LiberateLife.eu](https://LiberateLife.eu)



Discover a range of resources, practical tips and support to start your journey to living life to the full, with independence and peace of mind

Follow us:



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+46(0)18 697 20 00  
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## Regeneron is proud to support the work of The European Haemophilia Consortium

Regeneron is driven by a relentless pursuit to use science to benefit patients. We use our scientific knowledge and cutting-edge technologies to make significant advancements for people with serious diseases.

**REGENERON**<sup>®</sup>



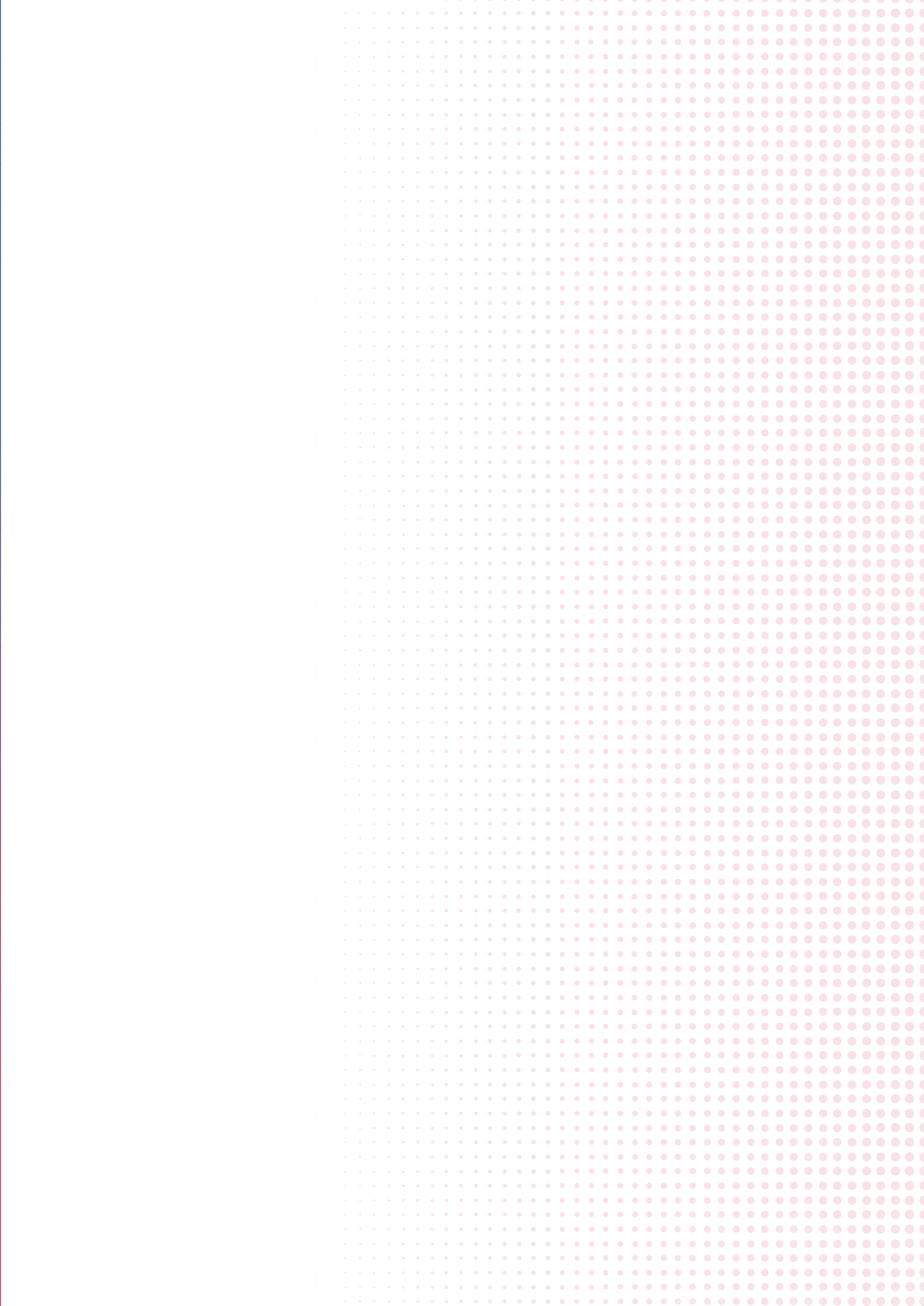
Yesterday, today and in the future -  
Living better with bleeding disorders

CSL is proud to be a longstanding partner of the European Haemophilia Consortium.

### Tradition and progress are in our DNA!

For over 50 years, we contributed significantly to major advancement in the treatment of bleeding disorders, such as haemophilia A / B and von Willebrand disease, with many of them being the first of their kind. Now and in the future we will continue to develop innovative and proven treatments to improve the lives of people with bleeding disorders.







## European Haemophilia Consortium

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office@ehc.eu



[ehc.eu](https://ehc.eu)



[community.ehc.eu](https://community.ehc.eu)



[academy.ehc.eu](https://academy.ehc.eu)



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