

## EHC STRATEGIC PLAN 2024 – 2028

This strategic plan outlines actionable steps across four pillars – Advocacy, Communication, Relationships, and Education – to address internal and external priorities and advance the mission of the organization in serving individuals with bleeding disorders.

### ADVOCACY

- **Focus on NMOs and Country Visits:**
  - Strengthen engagement with National Member Organizations (NMOs) through tailored support programs and regular communication in order to empower them and set a new dynamic;
  - Planning, where needed, country visits to better understand local needs and challenges and to provide direct assistance;
  - Attend NMO events to support advocacy initiatives and give greater visibility vis-à-vis decision-makers.
- **Inclusivity and Information Dissemination:**
  - Ensure inclusivity and information dissemination by providing comprehensive resources covering all bleeding disorders, including all ages, genders, and social backgrounds;
  - Promote awareness and understanding of extremely rare disorders to ensure no one is left behind;
  - Collect relevant data and conduct targeted surveys to support advocacy initiatives and ensure the proactive inclusion of the voices of patients in Europe.
- **External Presence:**
  - Increase presence in the field through active participation in relevant events, conferences, and initiatives organized by stakeholders and third parties.

### COMMUNICATION

- **Internal Communication Improvement:**
  - Strengthen communication channels between Committees and the Steering Committee (SC) to ensure alignment of goals and strategies;

- Facilitate effective communication between the European Haemophilia Consortium (EHC) and NMOs/Committees to foster collaboration, efficiency, and transparency;
- Develop internal guidelines for working with each other in a transparent way to promote consistency and fairness in internal operations;
- Ensure transparency in decision-making processes and resource allocation.
- **External Communication Enhancement:**
  - Redefine stakeholders and their relationships with the EHC, emphasizing mutual benefits and opportunities for healthy, transparent, and ethical collaboration;
  - Rebuild relationships with EU institutions, as well as non-EU stakeholders, to advocate for policies that support individuals with bleeding disorders, as well as the community at large;
  - Foster strong relations with the European Association for Haemophilia and Allied Disorders (EAHAD) to leverage expertise and resources;
  - Strengthen relationships with healthcare professionals, patient representative organizations, e.g. World Federation of Hemophilia (WFH), and other stakeholders through meaningful engagement to advance common goals and initiatives.

## EDUCATION

- **Focus on Multidisciplinary Care:**
  - Advocate for, promote, and educate on multidisciplinary care approaches to ensure holistic support for individuals with bleeding disorders.
- **Standards of Care for Other Bleeding Disorders:**
  - Engage in the development of standards of care or guidelines for specific populations and other bleeding disorders beyond haemophilia to address broader healthcare needs within the community and to function as an advocacy tool for better and more equitable diagnosis, access to treatments, innovation and quality of life;
  - Promote standards of care to improve diagnosis, access to treatment and multidisciplinary care based on relevant data and surveys.
- **Education Follow-up:**
  - Implement education follow-up initiatives to ensure continuous learning and skill development among patients, caregivers, and healthcare professionals;

- Provide resources and support for educational and scientific programs aimed at patients and caregivers to empower them with knowledge and autonomy;
- Address the specific needs related to ageing within the bleeding disorders community, including healthcare management and support services;
- Collect data on mental health and promote programmes and initiatives in the community to better advocate for access to service;
- Promote shared decision-making between patients and healthcare providers to empower individuals to make informed decisions about their treatment and care;
- Promote inclusivity at the national level of all other bleeding disorders.