A Letter to the Future

Sealed in the EHC Time Capsule on World Haemophilia Day, 17 April 2026

To Be Opened on World Haemophilia Day, 17 April 2039

Dear Future Generations and Future Selves,

As we write this letter in 2026, we stand at a moment of profound reflection, gratitude, and aspiration. Today, we honour not only the strides made in the care and lives of people with bleeding disorders but also the shared journey of resilience, advocacy, and community that has brought us here.

In 2026, the **European Haemophilia Consortium (EHC)** represents **49 national patient organisations** across the WHO European region, including 27 European Union Member States and most Council of Europe countries. Together, we speak for approximately **120,000 individuals** — and many more who live with rare bleeding disorders yet remain undiagnosed.

Looking back: achievements and progress

In 2026, the European bleeding disorders community stands stronger, more connected, and more visible than ever before.

Over decades, people with haemophilia, von Willebrand Disease and extremely rare bleeding disorders — alongside families, caregivers, clinicians, researchers, and advocates — have redefined what it means to live with these conditions.

1. Prophylaxis and innovative therapies have shifted expectations from survival to quality of life.

Through collaborative research, patient-led advocacy, and partnerships with clinicians and scientific entities, we've seen significant improvements in treatment options — from safer factor replacement therapies to innovative non-replacement treatments and gene therapy. These medical advances have helped reduce bleeding complications, improve quality of life, and expand therapeutic choices for many. While not all challenges are solved, the calibre and diversity of treatment options available today reflect decades of perseverance and scientific progress.

2. Cross-border collaboration has strengthened advocacy for equitable access to diagnosis, treatment, and care.

A core part of our mission has been to ensure equitable access to newborn screening and early diagnosis, safe and effective treatment and care for all people with bleeding disorders in Europe. The EHC, alongside its National Member Organisations and partners, has continually engaged with policymakers, European institutions, other organisations, and health authorities to influence policy frameworks that uphold patient access regardless of nationality, socioeconomic status, or bleeding disorder itself. Our advocacy has helped standards of care improve and brought attention to persistent disparities that must still be addressed. EHC's longstanding collaboration with healthcare professionals (HCPs) — including through partnerships with the EAHAD, the ERN-EuroBloodNet, and its own expert networks — has significantly advanced the understanding, diagnosis, and treatment of people living with bleeding disorders.

Across Europe and internationally, clinicians and patient advocates have repeatedly come together to jointly define practical, optimal standards of care aimed at harmonising treatment and ensuring high-quality, equitable care for all patients. These shared principles of care are grounded in ethical responsibility and evidence-based best practice, reflecting a collective commitment to improving health outcomes and quality of life for people with bleeding disorders.

3. Comprehensive care has increasingly meant multidisciplinary and holistic care — recognising physical, mental, and social wellbeing as inseparable.

As treatments improved and life expectancy increased, our perspective also evolved. Care could no longer focus solely on managing bleeds; it had to embrace the full life journey of a person living with a bleeding disorder.

In 2026, multidisciplinary care increasingly means coordinated support that includes physiotherapy, psychosocial and mental health services, pain management, dental care, genetic counselling, and social support. It reflects a recognition that living well is about far more than clinical stability — it is about mobility, confidence, relationships, dignity, and participation in society.

Thanks to therapeutic advances, many people with haemophilia and other bleeding disorders now reach a life expectancy comparable to that of the general population. This progress is extraordinary. Yet longevity brings new responsibilities. Ageing with a bleeding disorder requires systems of care that anticipate long-term challenges, support independence, and safeguard quality of life at every stage.

Through awareness campaigns, youth leadership initiatives, and community-led platforms, we have built a stronger, more connected, and more resilient community. But connection alone is not enough — advocacy remains at the heart of everything we do. In 2026, the EHC is calling for oral health to be formally integrated into national and European Rare Disease Plans, for deeper collaboration between haemophilia treatment centres and specialised dental services across Europe, and for the development of genuinely multidisciplinary models of care. We are also advocating for gender-responsive healthcare that recognises and addresses the distinct needs of women and girls with bleeding disorders — because their experiences have for too long been overlooked. These priorities share a common thread: the belief that comprehensive care must be exactly that — comprehensive, for everyone.

4. Patient voices have gained a place in policy discussions, research agendas, and regulatory decisions across Europe.

The EHC's sustained engagement in European health policy — including participation in consultations with regulatory bodies and advocacy coalitions — has strengthened the voice of patients in decisions that shape medical research, access to therapies, and healthcare systems. We have contributed lived experience and evidence to ensure that policies reflect real-world patient needs.

Voices from 2026

Here, we leave space for the voices that truly define our community as they reflect on their experiences and hopes for the future.

> ***"Looking back, I wish I had known that taking better care of my joints when I was younger would give me a longer and more active life with fuller participation in the activities I enjoy."*** *- Jim O'Leary, 70 years old*
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> ***"My promise for my healthy ageing is to work my hardest to stay independent and active as long as possible and encourage others in the bleeding community to do the same!"*** *- William McKeown, 34 years old*
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> ***"By 2039, I hope that every person with haemophilia lives in a world where safe, effective treatment is guaranteed, accessible to all, and no patient's future is limited by their diagnosis."*** *- Mirsad Jahija, 25 years old*
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> ***"My promise for my healthy ageing is to remember that being a carrier does not mean being unaffected, and to care for myself accordingly."*** *- Anja, 24 years old*
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> ***"In 2026, we remain faithful to the principle that has always guided us: 'Treatment for all'. To those reading this in 2039: remember those who did not live to see the progress you now enjoy, and let that remembrance move you to give back, stay engaged, and never let comfort replace compassion."*** *- Daniel Andrei, 48 years old*
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> ***"Looking back, I wish I had known that there were other options to manage heavy menstrual bleeding during premenopause instead of hysterectomy." -*** *Anonymous patient*
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> ***"My promise for my healthy ageing is to adapt as my body changes instead of fighting it." -*** *Anonymous patient*

> ***“As I age, I want to be the one making choices — not my body making them for me.” -*** *Anonymous patient*

> ***“My promise for my healthy ageing is to plan for old age as something expected, and not exceptional.” -*** *Anonymous patient*

These words are entrusted to you, future readers, as proof that progress was built on lived experience, courage, and solidarity.

Our hopes for 2039 and beyond

As we seal this letter, our hopes stand both bold and heartfelt:

✨ Universal diagnosis and early detection

We envision a future where every person born with a bleeding disorder — or at risk of one — receives early and accurate diagnosis, wherever they live in Europe, without delay. We envision a future where gender no longer determines how quickly or accurately a bleeding disorder is recognised.

✨ Equitable access across all regions

May no individual ever be denied essential treatment or comprehensive care due to financial barriers or geographic disparities. May health systems continue to evolve toward fairness and inclusion.

✨ Holistic, person-centred care

Beyond medical treatments, we hope for care systems that prioritise mental wellbeing, community engagement, ageing with dignity, and support that embraces the full life journey of every person affected by bleeding disorders.

As we entrust this letter to 2039, we hope that multidisciplinary, person-centred care has become not an ambition, but a universal standard — equitable, coordinated, and sustained throughout every stage of life.

✨ Sustainable innovation with patient priorities at the core

We envision an era of medical and technological innovation that emerges hand-in-hand with patient voices — where research, regulation, and clinical practice align to meet the needs of our community in meaningful and ethical ways.

✨ A flourishing, connected community

Above all, we hope that the bonds of trust, shared purpose, and solidarity that have defined our community continue to grow stronger across generations — empowering every person with knowledge, dignity, and a voice.

A message across time

To those opening this capsule in **2039**, we send our deepest respect and optimism. We hope you feel connected to us. We hope you recognise our intentions, even if the world around you looks very different. Let this letter remind you of where we came from, the battles we fought, and the hope that propelled us forward.

If there are challenges we have not yet solved, we trust that you carry the same determination that brought us this far. And if there are victories we only dreamed of, we celebrate them with you across time.

This letter is not an ending. It is a hand extended forward.

The work continues, but the legacy of courage, determination, and collective action lives on in each life it touched.

With hope and unity,

European Haemophilia Consortium

*On behalf of the **European Bleeding Disorders Community***

17 April 2026