

Towards Equitable Recognition and Care for Women and Girls with Bleeding Disorders

On this International Women's Day, the European Haemophilia Consortium (EHC) reaffirms its commitment to advancing equity for women and girls affected by bleeding disorders across Europe. Achieving this objective is fully aligned with the European Union (EU)'s commitments to gender equality, rare disease policy, and the strengthening of resilient, inclusive health systems under the European Health Union.

For too long, bleeding disorders have been perceived primarily as conditions affecting men. This outdated narrative has contributed to the persistent under-recognition, under-diagnosis, and under-treatment of women and girls living with haemophilia, von Willebrand Disease, and other inherited bleeding disorders. Across Europe, many women endure years of unexplained symptoms, delayed diagnosis, and restricted access to appropriate, specialist care. These disparities are reinforced by broader patterns of gender discrimination, where women's symptoms are too often minimised or dismissed, leading to bias, late diagnosis, and less optimal care than that provided to men. Tackling this requires not only policy change but also sustained awareness campaigns targeting the general population to challenge stereotypes, improve recognition of bleeding symptoms in women and girls, and promote timely access to appropriate care.

Addressing these inequities requires deliberate action at both the national and European levels.

1. Systematic Inclusion of Women in EU-Funded Research

Under programmes such as Horizon Europe and the EU's broader research and innovation framework, the systematic inclusion of women and girls in clinical trials, observational studies and real-world evidence generation must be strengthened and monitored.

The routine collection and reporting of sex-disaggregated data should be consistently required in EU-funded research. Without robust data reflecting women's lived experiences—including menstruation, pregnancy, childbirth and menopause—clinical understanding remains incomplete, and health inequalities persist.

We call on the European Commission, research funders, and regulatory bodies to ensure that gender-responsive research design is meaningfully implemented and evaluated across all relevant calls and partnerships.

2. Integration into European Registries, Reference Networks, and Clinical Guidelines

EU-supported registries and data infrastructures must comprehensively capture information on women and girls with bleeding disorders. Strengthened coordination through European

Reference Networks and cross-border collaboration provides a unique opportunity to harmonise data collection standards and improve diagnostic pathways.

Clinical guidelines developed or endorsed at the European level should explicitly address the diagnosis and management of bleeding disorders in women. Heavy menstrual bleeding, postpartum haemorrhage and gynaecological complications should be recognised as potential indicators of an underlying bleeding disorder—not normalised or overlooked.

Embedding these considerations within EU rare disease strategies and national implementation plans will support more consistent standards of care across Member States.

3. Improved Training for Healthcare Professionals

Improved education and training must form part of broader EU efforts to strengthen the health workforce. Investment through EU4Health and related initiatives should support awareness-raising and continuing professional development for general practitioners, gynaecologists, obstetricians, emergency physicians, and haematologists.

Earlier recognition leads to earlier diagnosis. Earlier diagnosis improves maternal outcomes, quality of life, and long-term health system sustainability.

Medical education frameworks and cross-border training initiatives should reflect the reality that bleeding disorders affect women as well as men.

The EHC stands ready to work with the European Commission, the European Parliament, Member States, and clinical stakeholders to ensure that women and girls with bleeding disorders are fully reflected in EU health, research, and gender equality policies.

On this International Women's Day, we reaffirm that equitable recognition and care for women with bleeding disorders is not only a matter of gender equality but also of delivering on the European Union's commitment to inclusive, evidence-based, and resilient health systems for all.