

Ensuring Access to Life-Saving von Willebrand Factor for All People with VWD

On von Willebrand Awareness Day, the European Haemophilia Consortium (EHC) draws attention to a critical gap in Europe's medicines policy: the absence of von Willebrand Factor (VWF) from the European Union's List of Critical Medicines.

VWF is a life-saving treatment for people living with von Willebrand Disease (VWD), the most common inherited bleeding disorder, affecting an estimated 0.6% to 1.3% of the general population. For many patients—particularly those with severe type 1 VWD, type 2 VWD and all patients with type 3 VWD—VWF-based therapies are not optional; they are essential. For these individuals, alternative treatments such as desmopressin are ineffective or unreliable.

Any disruption in the supply of VWF can have serious and potentially life-threatening consequences. Delays or shortages may lead to severe bleeding episodes, irreversible joint or organ damage, emergency hospital admissions, and, in the worst cases, death. Beyond the human impact, lack of access to VWF results in significantly increased healthcare costs, driven by emergency care and prolonged hospital stays, and delayed or cancelled surgeries, placing avoidable strain on public health systems.

Despite these realities, VWF is currently not recognised as a critical medicine at the EU level. This omission risks leaving people with VWD behind in Europe's efforts to prevent and mitigate medicine shortages—particularly those living with rare and severe forms of the condition who already face considerable uncertainty in their daily lives.

On this Awareness Day, the EHC urges national competent authorities to recognise von Willebrand Factor as a critical medicine and to include it in their national lists of critical medicines—a necessary prerequisite for its inclusion in the Union List of Critical Medicines. The EHC also calls on the European Medicines Agency (EMA) to support and facilitate this process. This essential step would help ensure a stable and reliable supply of VWF, safeguard patient health, and strengthen an EU approach to critical medicines that is inclusive, equitable, and responsive to the needs of people living with rare bleeding diseases.

No one living with a bleeding disorder should have to fear losing access to the treatment that keeps them safe and well. The EHC stands ready to collaborate with the EMA to ensure that the next update of the Union List of Critical Medicines reflects this urgent and unmet need, helping to protect the health and well-being of all people with von Willebrand Disease.