

EHC statement on the Union List of Critical Medicines

The European Haemophilia Consortium (EHC) calls on the European Medicines Agency (EMA) to include von Willebrand Factor (VWF) in the Union List of Critical Medicines.

VWF, a life-saving treatment for patients with von Willebrand Disease (VWD), is not included in the Union's List of Critical Medicines. The absence of VWF from the list could pose a risk to the health of patients who depend on it to manage their condition and avoid life-threatening bleeding events.

VWD is a rare bleeding disorder that affects an estimated between 0.6% and 1.3% of the general population. For patients with type 3 VWD, VWF-based therapies are essential, as desmopressin is ineffective. Similarly, patients with type 2 VWD often require VWF treatment due to variable responses to desmopressin. Delays or disruptions in the supply of VWF can have severe consequences, ranging from worsening health conditions to irreversible damage, hospital admissions, and even death.

In addition, shortages of VWF would lead to significantly increased healthcare costs, as patients are forced to seek emergency care and longer hospital stays. The lack of access to VWF compounds the burden on both patients and healthcare systems, causing unnecessary suffering and placing a heavy financial strain on public health resources.

While desmopressin is generally effective for treating type 1 VWD, it does not provide a suitable solution for patients with type 2 or type 3 VWD, underscoring the importance of a consistent and reliable supply of VWF for the full spectrum of VWD patients. The absence of VWF in the Union List of Critical Medicines could further exacerbate the risks for these patients, who are already dealing with the uncertainties of living with a rare disease.

The inclusion of VWF in the Union List of Critical Medicines would ensure that patients with VWD do not feel left behind in the European Union's broader efforts to address medicine shortages. It would also guarantee that these patients can access the essential treatments they rely on to manage their condition and maintain their health.

This inclusion will not only help protect the health of patients with VWD but also ensure that Europe's approach to critical medicines remains truly inclusive and equitable. We stand ready to collaborate to make this vital change, ensuring that the Union's List of Critical Medicines fulfils its potential to safeguard the health and well-being of all patients, particularly those with rare and life-threatening conditions.

The EHC stands ready to collaborate with the EMA to ensure the next update of the Union List reflects this urgent need.