Copenhagen, 22 March 2026

Call to action from the Nordic and Baltic patient organisations for rare bleeding disorders

On behalf of more than 7000 people living with rare bleeding disorders in the Nordic and Baltic countries, we as patient organisations wish to draw attention to the challenges that this patient group is particularly at risk of facing in the event of disruptions in the supply of critical medicines. Rare bleeding disorders are often treated continuously with success, while even short terminations of treatment can be invalidating or fatal. Our intention is to constructively support the ongoing European and national efforts to ensure stable deliveries of medicines used in the treatment of rare bleeding disorders such as haemophilia A and B, von Willebrand disease and other rare bleeding disorders.

Global uncertainty challenges the security of supply for critical medicines

In 2025, the European Commission presented the *Critical Medicines Act*, aimed at strengthening European supply chains, ensuring access to critical medicines, and increasing European production capacity. The proposal builds on lessons learned from the COVID-19 pandemic, the invasion of Ukraine, and more recent global crises, which together have highlighted vulnerabilities in Europe's current structures. The EU Commission emphasises that shortages of critical medicines may pose significant risks to patients and undermine the functioning of healthcare systems. The proposal also expands the definition of critical medicines to include treatments for rare diseases, which is particularly relevant for our patient groups.

Ensuring supply security for rare diseases requires special attention

The EU highlights significant vulnerabilities in the production chains of critical medicines, driven by geographical concentration, economic pressures, and dependence on third countries. It is therefore encouraging that the forthcoming *Critical Medicines Act* aims to diversify production and reduce these dependencies. As patient organisations, however, we wish to emphasise that for medicines used to treat rare diseases, this is an especially challenging task – one that requires dedicated attention.

The production of medicines for rare bleeding disorders differs markedly from conventional pharmaceutical manufacturing, not least because the patient population is very small compared to common diseases. Treatments for rare bleeding disorders such as haemophilia and von Willebrand disease are characterised by small batch sizes, often produced through highly specialised and globally distributed supply chains that are extremely sensitive to disruption. Production is currently concentrated among relatively few manufacturers and relies on biotechnological and complex

processes using specialised materials and components that are not necessarily EU-based.

The *Union list of critical medicines* identifies several life-saving medicines for which supply disruptions must be avoided, including multiple treatments for haemophilia. However, factor replacement therapy for the most common bleeding disorder, von Willebrand disease, is still not included on the list, despite repeated calls from the European association, the European Haemophilia Consortium.

Our Recommendations

In light of the above, we encourage the Nordic and Baltic Ministers of Health to:

- Support the EU's *Critical Medicines Act*, including the expansion of the definition of critical medicines to encompass treatments for rare diseases.
- Actively work towards joint regional and European solutions, particularly in relation to stock management and coordination — thereby preventing and mitigating medicine shortages for rare diseases such as haemophilia and von Willebrand disease.
- Strengthen regional dialogue on joint procurement and supply security, especially in the Nordic and Baltic regions, where small markets can benefit significantly from shared strategies.
- Incorporate medicine supply considerations into HTA processes, ensuring that long-term delivery stability becomes a parameter in the procurement of critical and specialised medicines.
- Advocate for key medicines for rare diseases — including von Willebrand factor — to be assessed for critical status where relevant.

Patients with rare bleeding disorders depend on stable access to specialised medicines. The European initiatives reflect a clear movement toward more coordinated, robust, and collective solutions. We believe that the Nordic and Baltic countries can play an active role in this development — also by keeping focus on the specific requirements that supply security for small and rare patient groups requires. We therefore hope that our perspectives can contribute to the ongoing political work.

From the Nordic Baltic Meeting, Copenhagen, 22 March 2026

Lithuanian Hemophilia Association	Latvian Hemophilia Society
Estonian Haemophilia Society	Haemophilia Society of Iceland
Swedish Bleeding Disorder Society	Finnish Bleeding Disorders Association
Norwegian Hemophilia Society	Danish Bleeding Disorder Society