



EHC Von Willebrand Disease Committee

Annual Report 2025

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Committee

- **Our goals:** Create awareness, recognition, support, and education about and for von Willebrand patients.
- **We are there for:** Patients with von Willebrand Disease and the people around them.
- **We meet:** monthly online and in person when possible, and at various events in the bleeding disorders community. We stay in touch via email and WhatsApp.



Julia Rauscher
Austria



Joanne Traunter
United Kingdom

Priorities

- Improve the **knowledge** of people with von Willebrand Disease in our community.
- Increase and improve **diagnosis and treatment options** nationally.
- Enable VWD **advocates** to work at the European level towards improving access to treatment and care for all patients with VWD.



Cathy Verbraeken
Netherlands



Laura Quintas Lorenzo
Spain



Baiba Ziemele
Latvia



Başak Koç Şenol
Turkey



Lena Steinbrecher
Germany

The work of the VWD Committee in 2025 was supported by:

Laura Quintas Lorenzo, EHC Steering Committee Liaison

Zita Gacser, EHC Community & Projects Lead

Enea Atroce, EHC Project Assistant (October – December)

Stavroula Koukouzeli, EHC Project Assistant (January – April)

Awareness

In September 2025, we released a **children's book, *Emma and the Playhouse***. Written by Cathy Verbraeken and illustrated by Mariana Ostanik, the book serves a dual purpose: **supporting children with VWD** in sharing their experiences and helping children without the condition develop understanding and compassion for their peers.



Advocacy

From September 19–21, 2025, we hosted the **VWD Summit** in Riga, Latvia. The programme entailed sessions which covered key **updates** on VWD, **best practices** and patient care challenges, and **policy engagement**.

Education

Over the course of the year, we developed the **National Member Organisations (NMOs) Handbook: A Comprehensive Guide to von Willebrand Disease (VWD)**. This initiative aims to **support NMOs**, patients, and other interested readers by offering a clear overview of VWD and practical guidance on how to improve patient care.

