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# **EHC Von Willebrand Disease Committee**

Annual Report 2025



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## Annual Report 2025

### 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.

### 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.



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

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**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.

