

Brussels, 24 September 2026

To: EHC National Member Organisations (NMOs)

Subject: Call for volunteers to join the VWD Committee

Dear EHC National Member Organisations (NMOs),

The European Haemophilia Consortium (EHC) is currently looking for seven (7) volunteers to join the VWD Committee for a period of three years (2027-2029).

The EHC VWD Committee was set up as a working group in 2020 to lead the 'EHC VWD Platform for Europe.' This platform promotes forming a European community of people with von Willebrand Disease (PwVWD) enabling them to find support and 'identity' while also promoting, building, and maintaining a network of European VWD advocates.

The working group was transformed into a committee in 2023, reflecting its evolution and development over the past three years. The Committee aims to increase and improve diagnosis and treatment options nationally and enable those VWD advocates to work at the European level and with other European partners towards improving access to treatment and care for all PwVWD.

The EHC is currently inviting applications for **seven (7) volunteers**:

- **Up to six (6)** people with lived experience of VWD, e.g., female patients with VWD, male patients with VWD, parents of a child with VWD. The Committee will strive for inclusion and balance of volunteers from different age groups, countries, and backgrounds.
- **Up to two (2)** healthcare professionals involved in the care of people with VWD, e.g., haematologists, physiotherapists, psychosocial specialists, nurses, dental care specialists, i.e., individuals who are part of the multidisciplinary care team.

The ideal candidate will:

- Be a member of or have a strong professional link with one of the EHC NMOs;
- Be fluent in English;
- Have the capacity for networking and promoting the message and activities of the European von Willebrand Platform;

- Commit to dedicating enough time to fulfil the activities carried out by the VWD Committee. The estimated time needed is one hour per week, plus one 1.5-hour online meeting per month, plus one face-to-face meeting per year in combination with a conference. The workload may require the ability to work on short notice and to meet tight deadlines;
- Have experience at either national or international level in carrying out activities or representing von Willebrand Disease in the bleeding disorder community.

To apply for this position, candidates will need to send:

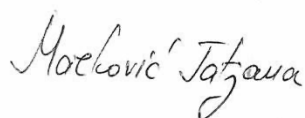
- The candidate's CV, outlining in particular relevant experience such as volunteering;
- The Membership Application form, which can be found on the last page of the Terms of Reference;
- A letter of recommendation from the NMO President outlining why they believe the candidate would make a great addition to the VWD Committee;
- The [Conflict of Interest Disclosure Form](#) duly completed and signed. The Conflict of Interest Policy can be found [on our Community website](#);
- The [Code of Conduct Form](#) duly completed and signed.

Applications should be sent to zita.gacser@ehc.eu by **9 November 2026** at the latest.

Please find attached the Terms of Reference, which further outline the Committee's objectives and the volunteer recruitment process. Candidates will be reviewed and selected by the EHC Steering Committee based on the criteria outlined above.

If you have any additional questions about this call for candidature, please do not hesitate to contact [Zita Gacser](#), EHC Community & Projects Lead.

Sincerely,



Tatjana Marković
EHC President

EHC VWD COMMITTEE TERMS OF REFERENCE 2025

The Von Willebrand Disease (VWD) Committee was set up as a working group in 2020 to lead the 'EHC VWD Platform for Europe.' This platform promotes the formation of a European community of people with von Willebrand Disease (PwVWD), enabling them to find support and 'identity' while also promoting, building, and maintaining a network of European VWD advocates. The working group was transformed into a committee in 2023, which reflects its evolution and development over the past three years.

Role

The von Willebrand Disease (VWD) Committee's objectives are:

1. To establish and promote a European community of people with von Willebrand Disease (PwVWD) under the auspices of the EHC, enabling the VWD community to find support and 'identity';
2. To promote, build, and maintain a network of VWD advocates for those affected by VWD across Europe;
3. To improve awareness, diagnosis, and treatment options nationally;
4. To work at the European level with other European partners (e.g., EAHAD, EMA, EDQM, EC, ERN-EuroBloodNet) to improve access to treatment and care for all PwVWD.

Composition

The EHC von Willebrand Disease Committee shall be composed of no more than nine members, including:

- Seven volunteers, and
- Two EHC supporting members.

Volunteers:

- Up to six people with lived experience of VWD, e.g., female patients with VWD, male patients with VWD, parents of a child with VWD. The Committee will strive for inclusion and balance of volunteers from different age groups, countries, and backgrounds.
- Up to two healthcare professionals involved in the care of people with VWD, e.g., haematologists, physiotherapists, psychosocial specialists, nurses, dental care specialists, i.e., individuals who are part of the multidisciplinary care team.

EHC supporting members:

- One EHC Steering Committee (SC) member,
- One EHC staff member.

The overall composition must ensure that the majority of volunteer members (at least five out of seven) are either patients with VWD or parents of individuals with VWD.

To a large extent, this body will seek expertise from the EHC Medical Advisory Group (MAG), and when needed, consult external experts. The EHC SC liaison, staff, and chair/co-chairs will also liaise with the other EHC committees and working groups to ensure that VWD patients within WBD, ERIN, etc., are taken into consideration.

Eligibility

The volunteers shall:

- Be members of or have a strong professional link with one of the EHC National Member Organisations (NMOs);
- Be fluent in English;
- Have the capacity for networking and promoting the message and activities of the European von Willebrand Platform;
- Commit to dedicating enough time to fulfil the activities carried out by the von Willebrand Disease Committee. The estimated time needed is one hour per week, plus one 1.5-hour online meeting per month, plus one face-to-face meeting per year in combination with a conference. The workload may require the ability to work on short notice and to meet tight deadlines;
- Experienced at either national or international level in carrying out activities or representing von Willebrand Disease in the bleeding disorder community.

Members of the VWD Committee will be proactive, leading and implementing their own work, with EHC staff support. It is mandatory to:

- Attend at least 75% of the virtual operational meetings of the VWD Committee per year,
- Attend at least one face-to-face operational meeting of the VWD Committee per year if such meetings are planned.

Selection process and mandate

The von Willebrand Committee members shall be selected as follows:

- EHC Steering Committee Member(s) shall be appointed by the EHC Steering Committee for a period of three years,
- EHC staff member(s) shall be appointed by the EHC Chief Executive Officer for a period of three years,
- An open call for volunteers shall be sent out to the EHC NMOs; the volunteers shall be selected on the basis of their compliance with the

criteria above and on the basis of the quality of their application. The EHC Steering Committee shall appoint the selected candidates for three years.

The EHC VWD Committee shall appoint a chair (or co-chairs) with a mandate of one year, who will be responsible for leading the work of the VWD Committee.

Members of the Committee can be nominated by *any* NMO of the EHC. Following the election, members will remain on the VWD Committee until the end of their mandate, provided they comply with the requirements.

If a member of the Committee does not comply with the above-mentioned requirements, he/she will be invited to step down as a Committee member. A member of the Committee may also be asked to step down in case of absence from at least three consecutive virtual meetings of the Committee.

If any member of the VWD Committee resigns during his/her mandate, the EHC will immediately open a call for candidates to fill the position with an equally qualified candidate.

Every decision regarding admitting new members or other strategic decisions should be examined by the Committee and voted on. A simple majority rule is applied. The decision on the new members' admission shall be approved by the EHC Steering Committee.

The SC liaison is a full member of the Committee with rights and duties.

Committee members agree to allow personal information to be used as per the EHC Privacy and Data Handling Policy.

Committee members agree to undertake their responsibilities as members of the VWD Committee in line with the EHC Code of Conduct and Conflict of Interest.

EHC VWD Committee Membership Application

(Please type)

Name: _____

Date of Birth: _____

NMO: _____

Phone: _____

Email: _____

Gender: _____

Please underline the relevant:

I am:

Person with VWD

Parent of a person with VWD (please specify): _____

Specialist (please specify): _____

Role in your NMO: _____

Please describe what, in your opinion, the European Haemophilia Consortium (EHC) should do to improve the situation of people across Europe who have VWD. What motivates you to apply to join this Committee? Please list any specific focus areas you are interested in and skills/activities that you could bring to the Committee to help its work. (Please use an extra sheet of paper for this if needed.)

Please enclose a short recommendation letter from your NMO!