

Brussels, 13 December 2024

To: EHC National Member Organisations

Subject: Call for volunteers to join the VWD Committee

Dear NMOs,

The European Haemophilia Consortium (EHC) is currently looking for two (2) volunteers to join VWD Committee till the end of its current term (end of 2026).

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 looking for two (2) volunteers who either are:

- patients with von Willebrand Disease, or
- parents of persons with VWD with children.

The volunteers shall:

- Be members 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 fulfill the activities carried out by the von Willebrand Committee. The estimated time needed is one hour per week, plus one 2-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 in the bleeding disorder community.

To apply for this position, candidates need to send:

- The candidate's CV, outlining in particular relevant experience such as volunteering,
- A motivation letter outlining briefly 1. what, in their opinion, the EHC should do to improve VWD patients' situation across Europe, 2. what motivates them to apply to join this Committee, and 3. what specific focus areas they are interested in and skills/activities they could bring to the Committee,
- A letter of recommendation from the NMO President outlining why they believe the candidate would make a great addition to the VWD Committee.

Applications should be sent to zita.gacser@ehc.eu by **9 January 2025** at the latest.

In attachment, you will find the Terms of Reference further outlining the Committee's objectives and the volunteer recruitment process. The 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 the EHC office.

Sincerely,



Miguel Crato
EHC President

EHC VWD COMMITTEE TERMS OF REFERENCE 2024

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 eight volunteers:

- A minimum of four patients with von Willebrand Disease, (it is recommended that two of them are men with VWD) of different ages and backgrounds;
- One to two parents of persons with VWD with children preferably of different ages, or
- Two multidisciplinary care professionals, e.g., a haematologist, physiotherapist, psychosocial specialist, nurse, and dental care specialist.

The EHC VWD Committee is supported by:

- One EHC Steering Committee (SC) member;
- One EHC Staff member.

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 to ensure that VWD of WBD, ERIN, etc., are taken into consideration.

Eligibility

The volunteers shall:

- Be members 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 fulfill the activities carried out by the von Willebrand Committee. The estimated time needed is one hour per week, plus one 2-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 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 von Willebrand 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 in case of compliance 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 equal candidate.

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