



Global VWD Call to Action

At the World Federation of Hemophilia (WFH) we believe all bleeding disorders matter.

Both women and men are equally affected by Von Willebrand Disease.

From January 27 – 29, 2017, the WFH, EHC and 12 individuals from bleeding disorder and rare disorder patient organizations from around the world gathered in Amsterdam to share their experiences on addressing the needs of people with VWD. The agenda included current perspectives from individual patients and patient organizations as well as action planning for a brighter future for people with VWD. Current perspectives and past experiences relayed from patient representatives and organizations revealed common, consistent themes which act as barriers to accurate diagnosis and management of VWD. These include misconceptions and lack of knowledge/awareness of VWD even amongst medical professionals; lack of homogeneity in providing care and many times lack of access to treatment; and feeling invisible as a patient with VWD.

As a result of the meeting, attendees recommended a greater focus be placed on VWD. Eight priority areas were identified:

<i>Improve diagnosis</i>	<i>Greater leadership and advocacy</i> <i>among the medical community, patient community, and related organizations</i>
<i>Consensus on standards of care (SOC)</i> <i>and global guidelines (GG)</i>	<i>Request that organizations</i> <i>incorporate</i> VWD into their work
<i>Address the misconception that</i> VWD is not a <i>serious</i> disease	<i>Destigmatize</i> the discussion <i>surrounding women's health</i>
<i>Patient empowerment for all</i>	<i>Safe, effective and easy to use</i> <i>treatments available everywhere</i>

The group calls on the entire global bleeding disorders community, including patient organizations and health care professionals, to integrate and provide recognition of VWD and other rare bleeding disorders into their work.

Each national member organization of the WFH is invited to sign onto this Call to Action to acknowledge the work that needs to be done, to make a commitment to recognizing VWD and other rare bleeding disorders by taking action to create awareness, resources and provide support to improve the lives of those living with VWD.

ORGANIZATION NAME

PRINTED NAME AND TITLE

DATE

SIGNATURE



Join us in the Global VWD Call to Action

The
[insert organization name]

commits to
[insert one step organization will take around VWD awareness, inclusion, diagnosis or management]

in the next year and will share any progress and/or outcomes with this group at that time.

Step by step process of signing on to the Call to Action:

- Review and discuss it with your board of directors
- Reflect on what actions your organization can implement
- To sign the call, there are two options:
 - Go to the WFH website to sign www.wfh.org/VWD
 - Print a copy and fax it to us at **+1-514-875-8916**

For more information about the Call to Action and the WFH VWD Initiative Program please visit the WFH website www.wfh.org/VWD and/or email us at vwd@wfh.org



WFH

WORLD FEDERATION OF HEMOPHILIA