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PUTTING VWD ON THE MAP

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The WFH VWD Global Group meeting 2019
Photo: WFH

In March 2019 I attended the World Federation of Hemophilia (WFH) VWD Global Group meeting in Amsterdam and was once again impressed by the commitment of my international colleagues to our cause of achieving change for people with von Willebrand disease (VWD).

Last year HFA joined the WFH global VWD call to action. As part of this work HFA was invited to become a member of the WFH VWD Global Group, which is a WFH global working group, dedicated to addressing the unmet needs and improving the quality of life of the VWD community.

In the meeting we discussed the international response to the global VWD call to action and ways to promote it further, barriers that some countries may experience, and strategies to engage other national member organisations of WFH in the call to action.

We also launched some digital stories about peer support from women with VWD on World Haemophilia Day

<http://tinyurl.com/connectBD>

AWARENESS AND ADVOCACY

We each gave presentations on the work we are doing in our own country to raise awareness of VWD and incorporate VWD into our activities. Each country has their own individual issues and I was very interested to see how my colleagues approach their issues and the strategies they use with advocacy and education. Panama, for example, with limited resources has an inventive and low budget social media awareness campaign with the hashtag #IamVonWillebrand (#YOSOYVW) and educational videos on Instagram and Facebook. Pakistan has very few health care services available for people with bleeding disorders and relies on humanitarian aid for its treatment products. Although they are active in their advocacy and education, a big issue is discrimination against women with VWD, particularly in marriage. In comparison, Canada, like Australia, is well-resourced in health care services and their focus is on diagnosing people with VWD, engaging men as well as women, and supporting self-advocacy to help receive appropriate VWD care in non-HTC health settings, such as emergency departments in hospitals or preparing for surgery. I spoke about Australia's work to be inclusive, in peer support groups and through activities such as the national conference and Bleeding Disorders Awareness Week and the education materials we have developed on VWD, including the new Female Factors resources and upcoming digital stories of women with VWD. The Group was particularly interested in our *Female Factors* magazine for young women with bleeding disorders and its dedicated sections and personal stories about VWD.

WORLD HAEMOPHILIA DAY

On the second day of the meeting we workshoped some social media messages for a special WFH VWD campaign in the lead-up to World Haemophilia Day. You may have seen some of the HFA messages about VWD and the Global VWD Call to Action from this campaign on our Facebook, Instagram and Twitter platforms. We also launched some digital stories about peer support from women with VWD on World Haemophilia Day - <http://tinyurl.com/connectBD>.



HFA VWD FOCUS GROUP

To help us with our strategic work around VWD, HFA has established the HFA VWD Focus Group. This is a group of community members with VWD who give feedback on specific questions and will review HFA education resources. Recently, for example, they gave suggestions on topics relevant to people with VWD for the 2019 Conference program and how to promote the Conference to people with VWD. They were also invited to participate in the international VWD clinical guidelines survey: supporting the development of the Australian clinical guidelines is HFA's specific commitment to the Global Call to Action, and as the Australian guidelines will be based on the international guidelines, this was an important activity.

If you would like more information about the HFA VWD Focus Group, or would be interested in participating, contact Suzanne at HFA:

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