

L-R: Sharon Caris, Emily Kempen and Suzanne O'Callaghan at the launch of the WFH Global VWD Call to Action at Congress

GLOBAL VWD CALL TO ACTION

WFH has commenced a global VWD Call to Action asking national member organisations and health care professionals 'to integrate and provide recognition of VWD and other rare bleeding disorders into their work.'

HFA has signed up to this Call to Action:

- To acknowledge the work that needs to be done
- To make a commitment to recognizing von Willebrand disease (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.

HFA's specific commitment is to participate in the development of national VWD diagnostic and clinical management guidelines. This work will be led by the Australian Haemophilia Centre Directors' Organisation (AHCDO) and will be based on the international guidelines, which are likely to be released in 2020. Some of you may be aware of the international VWD clinical guidelines survey, which was circulated for comment in July 2018, and is one of the steps in developing the international guidelines.

WHY THE CHANGE?

You may notice that HFA is now starting to use the term **von Willebrand disease** for VWD instead of **von Willebrand** disorder. This is part of our commitment to align with the global VWD Call to Action and the development of the international clinical guidelines. We are adopting the current internationally accepted term for VWD, which is **von Willebrand disease** – and this is what you will also see on the WFH website and the international clinical guidelines. **W**

PERSONAL STORIES

What is it like to live with a bleeding disorder?

What kinds of issues come up for parents, partners or siblings?

Visit the new **Personal Stories section** on the HFA website and hear from people from the Australian bleeding disorders community who have shared their experiences.

