

# Raising awareness globally for women with inherited bleeding disorders: World Federation of Hemophilia Symposium

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Figures in the World Federation of Hemophilia (WFH) global annual survey indicate, by their absence, that there is under-recognition of bleeding disorders in women. The WFH and its national member organisations (NMOs) are working to raise awareness and improve the diagnosis of care of women with bleeding disorders globally, regionally and locally. WFH initiatives include a global programme focused on improving the diagnosis, care and treatment of women with von Willebrand disease (VWD), and programmes involving education and training in conjunction with NMOs in countries including Honduras and Malaysia. NMOs in Slovakia, Latvia and Sweden describe their local activities. The Slovak Hemophilia Society is in the process of establishing

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a Women's Committee and considers peer support and network building as essential tools in addressing the issues faced by women with bleeding disorders. In Latvia, access to resources is difficult and von Willebrand factor is not available. There is concern in the Latvia Hemophilia Society that the fundamental human right of access to healthcare is not being met. It supports WFH initiatives through education and advocacy, and believes that the voices of women with bleeding disorders will be better heard through working together. The Swedish Hemophilia Society's Women's Project has worked since 2006 to promote better care for women with bleeding disorders and to raise public awareness. Despite resistance, their campaign to increase the identification of girls and women with VWD, improve diagnosis and care, and raise awareness has been well received by healthcare professionals and has had extensive media coverage.

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## THE WFH AND WOMEN WITH BLEEDING DISORDERS

The 2017 World Federation of Hemophilia (WFH) annual global survey included over 315,000 people with a bleeding disorder<sup>[1]</sup>. The results revealed a marked disparity in apparent gender distribution between haemophilia on one hand and von Willebrand disease (VWD) and other bleeding disorders on the other. According to these data, women account for only 3% of people with haemophilia A and 5% of those with haemophilia B, whereas 61% of people with VWD are women. The figures for haemophilia are unrepresentative of the worldwide gender distribution, and the WFH aims to address this under-recognition through a number of targeted initiatives, exemplified by its work to promote awareness and improve the care available to people with VWD.

### WFH global initiatives

World Hemophilia Day in 2017 was focused on the theme *Hear Their Voices* and raising awareness of girls and women affected by bleeding disorders. In 2018, the WFH created its first committee for women with inherited bleeding disorders, with representation from the United States, Europe, the Middle East, India and Australia. The Committee has organised a pre-congress

session for the 2020 WFH Congress covering the challenges of bleeding disorders in women and girls and how to improve care. The Congress itself will include sessions on women with haemophilia, aging and women, and VWD, and will also revisit a WFH global initiative, the VWD Call to Action, to improve care for VWD launched at the 2018 Congress in Glasgow, Scotland.

Together with the US National Hemophilia Foundation and the International Society for Thrombosis and Haemostasis, the WFH is collaborating with the American Society of Hematology on new clinical guidelines for the management of VWD. Starting in 2018, the process has included a stakeholder survey that was translated into three languages, which generated over 600 individual responses from people with VWD, caregivers, clinicians and other healthcare professionals. The guidelines will be published in 2020.

The WFH is also implementing a global programme to increase the diagnosis of VWD, improve care and treatment, raise awareness, and create a global community of people affected by VWD. This includes outreach initiatives, training for healthcare professionals, patients and families, and the development of advocacy tools. As part of the programme, in 2018 the WFH organised a national workshop in Algeria and a regional symposium in India for countries in the South and East

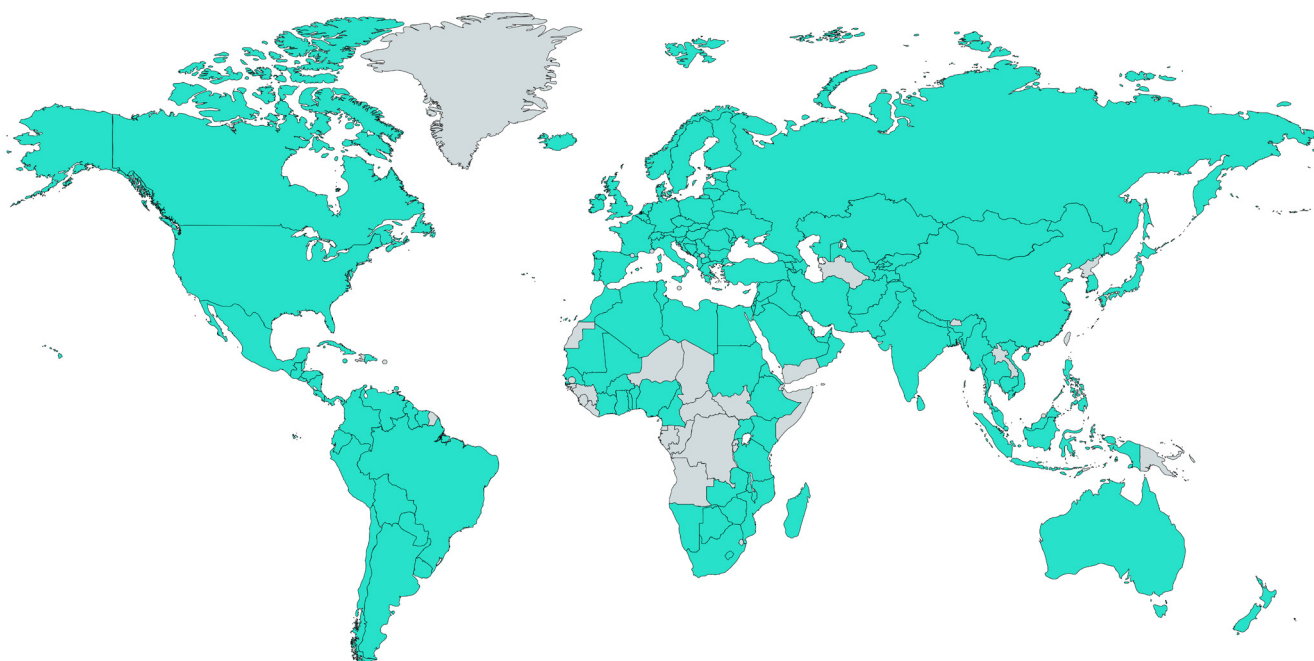


Figure 1. Distribution of National Member Organisations (NMOs) of the World Federation of Hemophilia (WFH) at country level. The WFH has implemented initiatives aimed at improving diagnosis and care for women with bleeding disorders around the world, working with NMOs and haemophilia treatment centres. Present in 140 countries, many NMOs are working to increase awareness at a national level – working together is key.

Asia region to enhance clinical knowledge of care and treatment of VWD and women with bleeding disorders among healthcare professionals. A WFH global working group comprised of a number of national member organisations (NMOs) has come together to address the unmet needs, and is dedicated to improving the quality of life of the VWD community. To date, 37 NMOs have signed up to a global call to action recognising VWD, the importance of its inclusion in their work, and as an act of solidarity. The call states explicitly that men and women are equally.

### WFH's reach

Alongside its global initiatives, the WFH has supported projects to educate and empower women affected by bleeding disorders in economically developing countries. In Honduras, for example, women and their families have participated in projects focused on the mothers and other relatives of people with bleeding disorders to promote self-employment and support training to help improve their quality of life. In Malaysia, the Kelab Haemostasis Wanita (Women's Haemostasis Club) aims to improve diagnosis and treatment among women overall and pregnant women in particular, to provide education and raise awareness, and to strengthen leadership skills through workshops, social media and using educational materials. The WFH supported a national forum on women with bleeding disorders and haemophilia in Columbia. The Nicaraguan Association of Hemophilia lobbied the Nicaraguan government to add desmopressin and tranexamic acid to the country's registry. The Hemophilia Society of Bangladesh is optimising resource use to create awareness of VWD at the same time as haemophilia.

### WOMEN WITH BLEEDING DISORDERS IN SLOVAKIA

Slovakia is a new country: it was established in 1993 following the peaceful separation of Czechoslovakia, and has a population of 5.4 million. Specific care for bleeding disorders in Slovakia was first established in the late 1950s, with the national haemophilia centre in the capital, Bratislava, opening in 1974. There are now three regional comprehensive care centres and 38 local haemophilia centres, which in 2018 provided 7.7 IU per capita of factor VIII, 27% of which was recombinant factor. The first extended half-life factor was introduced in 2018 and emicizumab was used for the first time in 2019.

Slovakia's National Registry of Bleeding Disorders includes 612 people with haemophilia, of whom 130 (21%) are women known to have the haemophilia gene,

and 818 with VWD, of whom 430 (52%) are women. The Registry includes a further 36 women with platelet disorders and 592 women with other bleeding disorders.

Women with bleeding disorders have always been afforded equal status to men in the Slovak Hemophilia Society, which was founded in 1990, and they play an active role in its initiatives (in mixed sex groups where appropriate). The Society provides various special activities for women, including the provision of consultations with haematologists and gynaecologists at its summer camps. Haemophilia treatment centres provide healthcare from the onset of menarche, which is further supported through the education of young girls and their mothers in various ways, including peer support from other women with bleeding disorders within the Society.

The Slovak Hemophilia Society is now planning to establish a Women's Committee that will focus more sharply on the issues affecting women and girls with bleeding disorders, working in cooperation with haemophilia treatment centres, and further encouraging the creation of relationships and peer networks within the Society. The Women's Committee will also help to promote the message that haemophilia is not the only bleeding disorder.

### WOMEN LOCALLY AND GLOBALLY: THE LATVIA HEMOPHILIA SOCIETY

Among Latvia's population of 1.93 million, 283 people are registered with a bleeding disorder. Access to resources is difficult when other more frequent disorders require funding; if the country is to continue to improve mortality associated with postpartum haemorrhage, it needs to recognise the needs of the bleeding disorders community. Von Willebrand factor is not available, so people with VWD are treated with desmopressin.



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While global maternal mortality is continuing to fall, issues around pregnancy and childbirth still account for over 300,000 deaths a year globally. Postpartum haemorrhage accounts for around 27% of cases, and it is estimated that bleeding disorders are a factor in around 1% of these (around 830 cases annually)

Access to the highest attainable standard of health has been identified as a fundamental human right since the publication of the World Health Organization (WHO) Charter in 1949, and there is a legal obligation on states to ensure this<sup>[2]</sup>. Core components of this include the availability, accessibility, acceptability and quality of healthcare, which should be safe, effective, people-centred, timely and equitable. The WHO's sustainable development goals for 2030 includes targets for healthcare. Targets related to maternal mortality in particular, but also around areas such as the preventable deaths of newborns and children under five years old, universal access to sexual and reproductive healthcare, and increasing health financing and the recruitment, development and training of healthcare professionals, are all of relevance to the under-diagnosis and lack of awareness of bleeding disorders in women.

Global maternal mortality decreased from 385 per 100,000 live births in 1990 to 216 in 2015<sup>[3]</sup>. Across the European Union, the decrease was from 18 per 100,000 births in 1990 to 8 in 2015; in Latvia, it was from 48 per 100,000 births in 1990 to 18 in 2015 (a drop of 63%)<sup>[3]</sup>. However, also in 2015, 303,000 women globally died due to causes related to pregnancy or childbirth, and 83,100 women died as a result of postpartum bleeding or haemorrhage (PPH). It is estimated that around 1% of cases of PPH are related to bleeding disorders<sup>[4]</sup>, and the higher the risk of bleeding, the higher the risk of dying from bleeding.

Against this background, the role of the WFH and its NMOs in education and advocacy for women with bleeding disorders is essential. The Latvia Haemophilia Society provides education, advocates for care and treatment for national plans and treatment guidelines, and conducts specific campaigns for VWD. It promotes messages from the WFH via its website, although access to published resources in the local language is difficult. In Latvia – as in many other countries – awareness of bleeding disorders among physicians is low and it is widely believed that bleeding disorders do not affect women. When relatively few people are affected, it can be difficult for the voice of the bleeding disorders community to be heard – but working together, locally and globally, can help to overcome this.

## THE WOMEN'S PROJECT, SWEDISH HEMOPHILIA SOCIETY

The Swedish Hemophilia Society's Women's Project has its roots in a 2006 initiative to build a network of women with bleeding disorders. It has three main goals:

- To educate and empower women with bleeding disorders
- To promote better care for women with bleeding disorders
- To raise public awareness about women with bleeding disorders.

Between 2007 and 2014, the four women who make up the project group organised nine network meetings with healthcare professionals, provided training and achieved extensive coverage in the print media, including the country's biggest-selling newspaper. The project posts stories, information and Q&As on its own page on the Swedish Hemophilia Society's website, and in 2008 published a book about being a woman with a bleeding disorder. The book was sent to media outlets and health facilities, and is available in some public libraries.

In 2009, and against some opposition, the board of the Swedish Hemophilia Society granted permission to form its first Women's Committee. As part of the Society's fiftieth anniversary congress in 2014, the Women's Committee gave two lectures and staged the exhibition 'Period Pieces', highlighting the issues faced by women with bleeding disorders, which was featured on Swedish national television. A subsequent proposal by the Women's Committee that the Society should change its logo (silhouettes of a man and a boy) to a gender-neutral logo was refused by the Board.

Funding for the Women's Project was first sought in 2011. The application was initially declined, but the proposal was resubmitted in 2014 to the Swedish Inheritance Fund, with a statement that there were 50,000 women in Sweden whose quality of life was being impaired by undiagnosed mild VWD: the project would reduce this burden by raising awareness, and have the knock-on effect of helping women with other bleeding disorders. Funding was approved and a full-time project manager was appointed for three years from 2015 to 2018, supported by the Women's Committee and an administrator.

The project's primary goals were:

- To increase identification of girls and women with bleeding disorders in Sweden
- To emphasise the importance of receiving a diagnosis and proper treatment
- To raise awareness among both healthcare professionals and the general public of the challenges faced by women and girls with bleeding disorders.

Educational activities included exhibiting at healthcare sector events, lectures to healthcare professionals





'Mini Mary' (left) was used by the Swedish Hemophilia Society's Women's Project to convey the impact of living with a bleeding disorder in meetings with school health professionals, while the 'Menstrual Cycle' (right), decorated with lingonberry and menstrual cups, stimulated interest at Sweden's most important political forum



and in youth groups and schools (in which concepts such as 'Mini Mary' were used to convey the impact of living with a bleeding disorder), participation in congresses for gynaecologists and school physicians, and training project ambassadors. A campaign website (<https://blodarsjuk.nu>) was set up offering personal stories, answers to frequently asked questions and a quiz, as well as a short film about suffering bleeding episodes in silence. So far, this has been spread via social media, but there are plans to show it in cinemas and as a television commercial. Again, these activities have received generous coverage in the press. The project was also involved in Almedalen week in 2015, Sweden's most important political forum, where interest was stimulated by the 'Menstrual Cycle', a red bicycle decorated with lingonberry and menstrual cups.

Outcomes to date suggest that the Women's Project is succeeding. Awareness is increasing among those healthcare professionals who repeatedly attend fairs, and women involved in the project have been invited to speak to undergraduate medical students, and to contribute to guidelines for primary care on the investigation of bleeding disorders in girls.

It is too early to determine whether the project has increased diagnoses of bleeding disorders among girls and women in Sweden. Since 2018, the Women's Committee has continued the work of the Women's

Project on a voluntary basis and, in collaboration with treatment centres, is developing a starter kit for newly diagnosed women.

## DISCUSSION

Members of the audience felt that it would be useful for NMOs to share their experiences and resources to avoid duplication and save time. The European Haemophilia Consortium (EHC) is currently compiling a library of resources and invited participants to submit any materials they would like to share with NMOs, also reminding participants that grants are available to NMOs to develop their own resources. Speaking on behalf of the Swedish Women's Project, Anna Tollwé said she would be happy to share resources subject to any intellectual property constraints.

The meeting was urged not to overlook rarer bleeding disorders through its focus on women with VWD: campaigns should be inclusive. It was pointed out that initiatives promoting awareness of the more common disorders can act as pathfinders for less well known disorders and that, by drawing attention specifically to women, awareness of other bleeding disorders would also increase.

Raising awareness of bleeding disorders in women and the challenges faced by the women and girls who have them has not been without obstacles, but in general there has been good progress. The

Swedish Women's Project encountered controversy and resistance to change, but was able to tackle these issues in a conciliatory way, building bridges through dialogue and patience. The haemophilia community in Sweden has not always been forward-looking, but women members of the NMO are now fully accepted. In Latvia, many members of the Hemophilia Society are men, but a woman was elected as its president. Ultimately, men and women are part of the same bleeding disorders community and share its aims.

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