

Advocacy worldwide for women with bleeding disorders

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Raising awareness that bleeding disorders affect women – not just men – is a key part of advocacy initiatives around the world. The European Haemophilia Consortium (EHC) and national patient organisations have run successful campaigns, with a wealth of information for women and girls with bleeding disorders and non-specialist healthcare professionals, including bleeding assessment tools, patient stories, blogs and videos. Some hold conference sessions and webinars devoted to bleeding disorders in women. By drawing on ideas and resources already available, patient organisations and other groups for women with bleeding disorders can fast-forward their advocacy plans, improve awareness and accelerate change.

Keywords: *Women with bleeding disorders, Advocacy, Raising awareness, Patient organisations*

EHC ADVOCACY

Advocacy for women with bleeding disorders (WBD) at the European Haemophilia Consortium (EHC) has been led by the Women and Bleeding Disorders Committee since 2018. Through communication and collaboration with national patient organisations across Europe, the Committee gathers data and feedback about the unmet needs of WBD, priorities for raising awareness, establishing initiatives and producing resources. The

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data received by the Committee from questionnaires completed by patient organisations and other stakeholders are of immense value in driving policy and bringing about change.

The Women and Bleeding Disorders Committee website hosts a growing range of videos on issues that are important to WBD, including bruising, menstruation and dental problems, and welcomes further contributions. The video *Women and Bleeding Disorders: Untold Stories*^[1] gives a voice to women from across Europe who shared compelling, moving and, in many cases, uplifting accounts of living with bleeding disorders. The publication *Bloody Beautiful*^[2] similarly collects diverse experiences of living with a bleeding disorder from women in Belgium and the Netherlands. The educational app *EHCUCATE*^[3] includes useful information on novel therapies. To mark International Women's Day 2022, the EHC produced its downloadable Diagnosis Quiz^[4] flyer (Figure 1) in multiple languages and in a template format enabling translation into other languages, together with social media cards to raise awareness of bleeding disorders in women. The Diagnosis Quiz was originally developed by the Women's Committee (Commission Femmes) of the French Haemophilia Association (Association française des hémophiles) in 2017^[5,6] and is now used in many countries.

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The EHC increasingly works with healthcare providers to inform and advise about the needs of WBD and, working with the European Association for Haemophilia and Allied Disorders (EAHAD), was key in the development of the Principles of Care for Women and Girls with Inherited Bleeding Disorders [7]. Presentations at the EHC's annual conference, round tables and webinars are also important opportunities for advocacy and help to maintain a high profile for WBD. The EHC shares information on good and bad practice reported by national patient organisations in Europe and other stakeholders. This can be used by individuals to advocate on their own behalf, by other patient organisations to advocate nationally, and by the EHC at a pan-European level.

The recent evolution of the European Inhibitor Network into the European Rare and Inhibitor Network will expand opportunities for stakeholder contributions and advocacy, including for ultra-rare bleeding disorders. Young women are increasingly being nominated by national patient organisations for the EHC's annual Youth Leadership Workshop – designed to benefit participants and patient organisations by supporting the growth and development of volunteer communities.

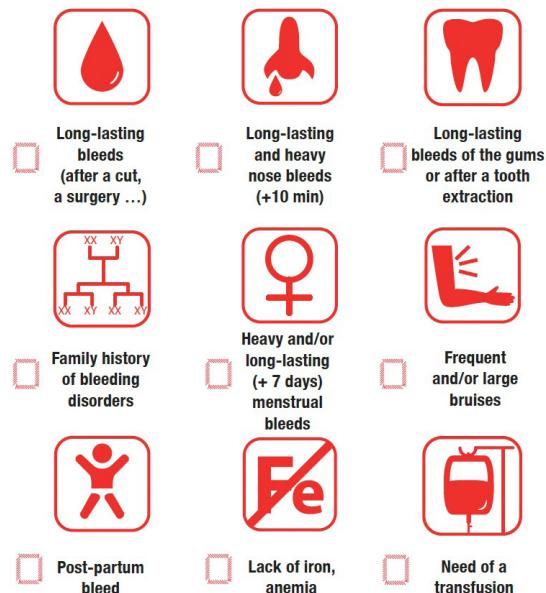
AWARENESS CAMPAIGNS AROUND THE WORLD

Awareness campaigns from grassroots organisations are a major part of advocacy for WBD. These include spreading information and education about the need for obstetrics/gynaecology, musculoskeletal, gastrointestinal and psychosocial support and services as part of routine care within treatment centres.

Talking Red is a campaign by the UK Haemophilia Society to empower women, dispel myths and share knowledge [8]. Women can assess their bleeding symptoms using the Talking Red Symptom Checker, find out about getting a diagnosis and going to a haemophilia treatment centre, and read about the real-life experiences of other women like them. Women are encouraged to post and share photos on social media using the #TalkingRed hashtag. There is also an annual Talking Red event with expert speakers, and downloadable materials for women to raise awareness about WBD.

In Canada, Let's Talk Period aims to increase awareness of the signs and symptoms of bleeding disorders and has a self-administered bleeding assessment tool (SELF-BAT) designed to inform women and girls about their bleeding and guide them towards the help they need [9]. The website includes blogs and a

DIAGNOSIS QUIZ WOMEN & BLEEDING DISORDERS



Here are the 9 main symptoms which could indicate the presence of a bleeding disorder for you, a woman or a girl you know.

If you have checked at least two of the boxes please do seek counselling and set up an appointment with a physician specialised in hematology or at your local hospital in order to determine if you are a person with a bleeding disorder.

Figure 1. Diagnosis Quiz for Women & Bleeding Disorders, available in multiple languages via the EHC website [4]

wide range of resources for patients, teachers, nurses and primary care providers.

From the Hemophilia Federation of America comes the Blood Sisterhood app [10] – for WBD to track their periods, record their treatment and share information with their healthcare provider.

In Ireland, Know Your Flow [11] is a public awareness campaign by the Irish Centre for Vascular Biology in collaboration with the Irish Haemophilia Society and the Royal College of Surgeons in Ireland (RCSI), helping women to recognise if their periods are heavier than normal and when heavy periods could be a sign of a bleeding disorder. The Know Your Flow website provides information and advice, including when and how to seek help and links to the Irish Haemophilia Society and World Federation of Haemophilia (WFH).

In Sweden, a Public Awareness Campaign [12] run by the Swedish Haemophilia Society (Förbundet Blödarsjuka i Sverige) is active in schools and conferences, advocating for women and girls with bleeding disorders. Website visitors can download

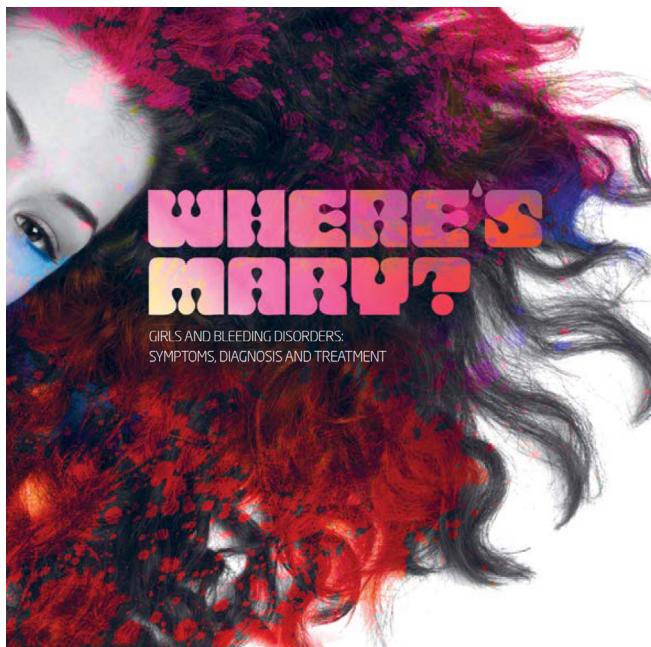


Figure 2. 'Where's Mary?' booklet produced by the Swedish Haemophilia Society

'Where's Mary?' was devised and written by Maneka Ghosh and Anna Tollwe.

'Where's Mary?'^[13] – a booklet about WBD based on stories from girls with bleeding disorders (Figure 2). Through this, they can access a Blood Loss Assessment Chart, read personal stories of WBD, learn about bleeding disorders and answers to common questions, and ask their own questions.

The Women's Committee (Commission Femmes) of the French Haemophilia Association (Association française des hémophiles) was established in 2006 and advocates for diagnosis, better care and support for WBD^[14]. Alongside a range of information leaflets on bleeding disorders in women for the public and for non-specialist health care professionals, recent activities have included the Facebook campaign 'Women Bleed Too'. The campaign comprised webinars about identifying symptoms and making a diagnosis, treatment, care and support, and the impact of bleeding disorders on everyday life for women. A YouTube video^[15] has also helped to raise awareness.

ADVOCACY FOR CHANGE

The initiatives described represent a sample of the advocacy campaigns happening across Europe and beyond that are seeking to improve the experiences of WBD. Advocacy plays a key role in raising awareness and changing the lives of WBD for the better by helping to identify bleeding symptoms and improve diagnosis, ensuring that women receive the care they need at

all stages of life, and enabling them to live a good quality of life. These ideas and resources are available for patient organisations and other groups for women with bleeding disorders to draw on – and can help fast-forward advocacy plans, improve awareness and accelerate change.

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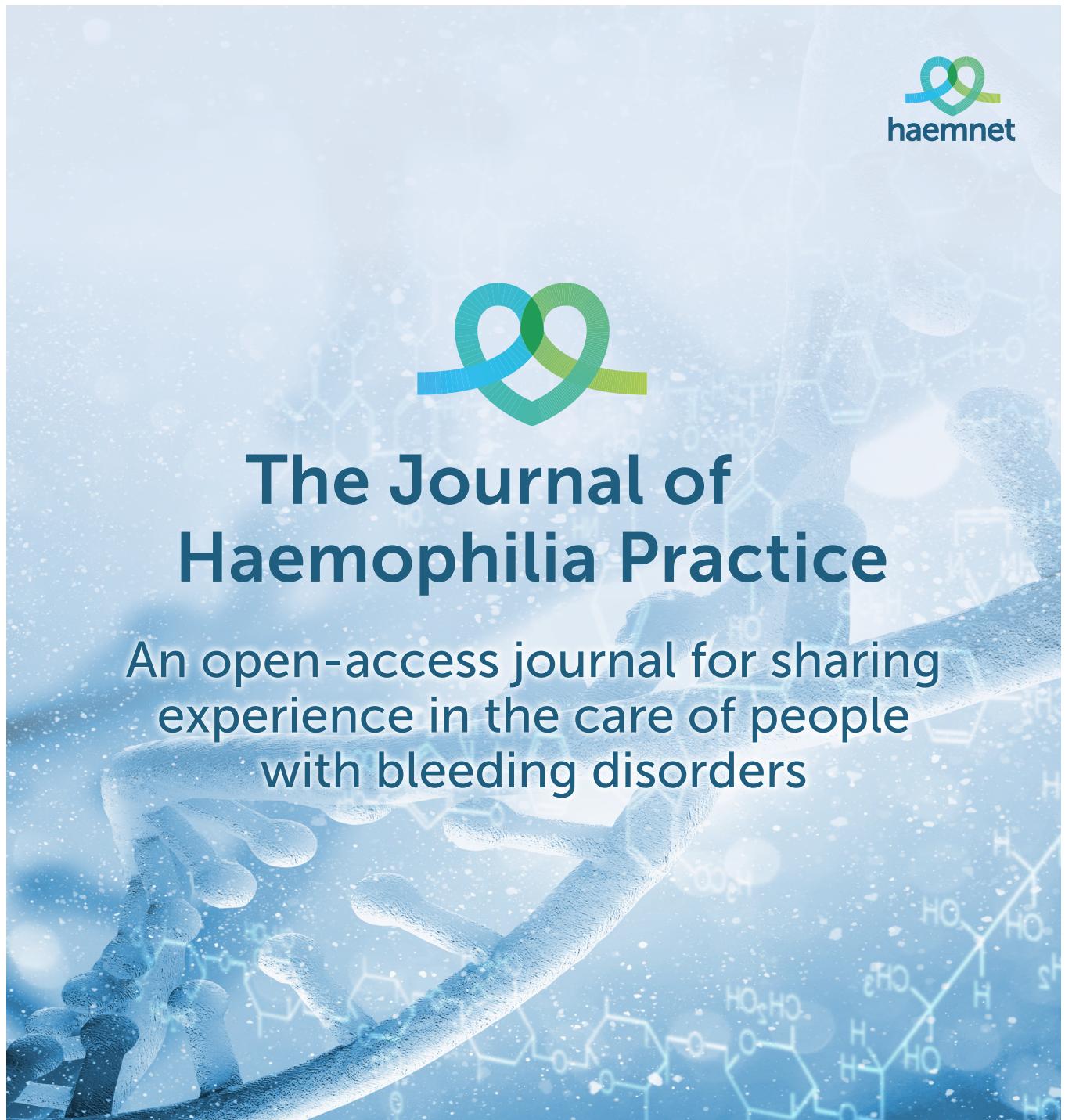
REFERENCES

1. European Haemophilia Consortium. Women and Bleeding Disorders: Untold Stories. 2019. Available from <https://www.ehc.eu/bleeding-disorders/women-with-bleeding-disorders/> (accessed 1 September 2022).
2. Keys I. Bloody Beautiful: Women in the Lead. 2018. Shire Netherlands BV. <http://www.ingeborgkuys.nl/bloody-beautiful/> (accessed 1 September 2022).
3. European Haemophilia Consortium. EHC introduces new educational app on rare bleeding disorders & novel therapies. February 2021. Available from <https://www.ehc.eu/ehc-introduces-new-education-app-on-novel-therapies/> (accessed 1 September 2022).
4. European Haemophilia Consortium. EHC Women's Committee marks International Women's Day. February 2022. Available from <https://www.ehc.eu/ehc-womens-committee-marks-international-womens-day/> (accessed 1 September 2022).
5. Association française des hémophiles. Rétrospective de la Commission Femmes. 17 February 2021. Available from <https://afh.asso.fr/2021/02/17/retrospective-de-la-commission-femmes/> (accessed 20 September 2022).
6. Association française des hémophiles. Commission Femmes. Quiz – Diagnostic. Available from https://afh.asso.fr/wp-content/uploads/2017/09/FR-fich-diagnostic_WEB.pdf (accessed 20 September 2022).
7. van Galen K, Lavin M, Skouw-Rasmussen N, et al.; European Haemophilia Consortium (EHC) and European Association for Haemophilia and Allied Disorders (EAHAD). European principles of care for women and girls with inherited bleeding disorders. *Haemophilia* 2021; 27: 837-847. doi: 10.1111/hae.14379.
8. The Haemophilia Society. Talking Red – supporting women with bleeding disorders. Available from <https://haemophilia.org.uk/support/talking-red/> (accessed 1 September 2022).
9. Let's Talk Period. Available from <https://letstalkperiod.ca> (accessed 1 September 2022).
10. Hemophilia Federation of America. Blood Sisterhood: a new app for women with bleeding disorders. Available from <https://www.sisterhoodapp.com> (accessed 5 September 2022).

11. Know Your Flow. 2022. Available from: <https://www.knowyourflow.ie> (accessed 5 September 2022).
12. Förbundent Blödarsjuka I Sverige. Girls with bleeding disorders. Available from <https://blodarsjuk.nu/en/home/> (accessed 5 September 2022).
13. Förbundent Blödarsjuka I Sverige. Var är Mary? Tjejer och blödarsjuka: symtom, utredning och behandling. 2016. Available from https://www.svenskalag.se/fbis/dokument/dffe2502-5f15-48dd-bd5b-d1d5d2751067/Var_ar_Mary-FBIS-broschyr_XS.pdf (accessed 15 September 2022).
14. Association française des hémophiles. Commission Femmes. Available from <https://afh.asso.fr/avec-lafh/notre-organisation-en-chiffres/les-commissions/femmes/> (accessed 20 September 2022).
15. Association française des hémophiles. Ensemble, pour un #Diagnosticpourtoutes. 8 March 2022. Available from <https://www.youtube.com/watch?v=GUfytYX2jrA> (accessed 5 September 2022).

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