sciendo

The Second European Conference on Women and Bleeding Disorders, Basel, Switzerland, 10-12 May 2022

Naja Skouw-Rasmussen, Evelyn Grimberg, Declan Noone

Women with bleeding disorders (WBD) face unique challenges, and a historical lack of visibility has resulted in delayed diagnosis, poor access to treatment and exclusion from potentially life-changing research. Progress is being made in raising awareness of the unmet needs of WBD but there is still a long way to go – both within the bleeding disorder community and externally [1].

Since the First European Conference on Women and Bleeding Disorders, held so successfully in 2019, the global pandemic prevented the European Haemophilia Consortium (EHC) from holding a second conference until 2022. However, the momentum behind addressing the issues faced by WBD has continued. In 2020, the World Federation of Hemophilia's first global summit on women and girls with bleeding disorders was held virtually. The EHC has also not been idle. The Women and Bleeding Disorders Committee has been very active, sharing information online, including through webinars and networking opportunities, and developing resources including advocacy strategies for reaching out to and on behalf of WBD.

NAJA SKOUW-RASMUSSEN
European Haemophilia Consortium, Brussels, Belgium

EVELYN GRIMBERG
European Haemophilia Consortium, Brussels, Belgium

DECLAN NOONE
European Haemophilia Consortium, Brussels, Belgium.
Email: declan.noone@ehc.eu

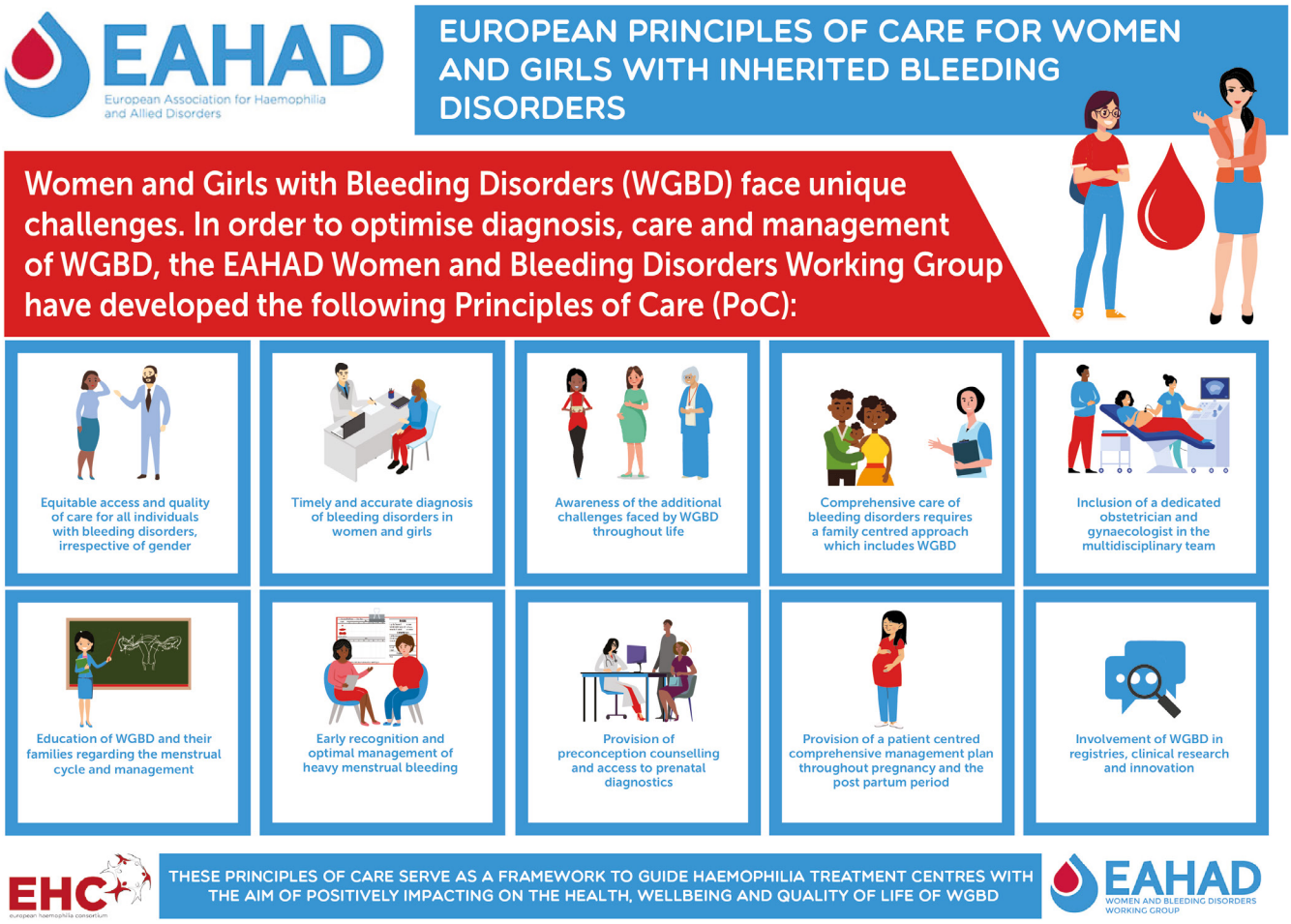
REPORTS FROM THE SECOND EUROPEAN CONFERENCE ON WOMEN AND BLEEDING DISORDERS

One landmark achievement was the development and publication of the Principles of Care for Women and Girls with Inherited Bleedings Disorders by the EHC and the European Association for Haemophilia and Allied Disorders (EAHAD) in 2021 (Figure 1) [2]. The 10 key evidence-based principles aim to raise awareness of bleeding disorders in women, standardise their care, ensure access to a truly comprehensive care team for every woman, and thus improve their health, quality of life and wellbeing. As such, they have the potential to drive significant long-term change for WBD.

The Principles are the result of a collaboration between clinicians and the patient community. Alongside strengthening that partnership, they are designed to redress the imbalance for those who may be unaware of the clinical, psychological and practical support needs of WBD at haemophilia treatment centres. As such, they are a valuable resource for national member organisations (NMOs) of the EHC, clinicians, haemophilia treatment centre managers and other stakeholders to use when advocating on behalf of WBDs for enhanced services. These enhancements include enabling dedicated obstetricians, gynaecologists and geneticists to work alongside haemophilia specialists in clinics.

J Haem Pract 2022; 9(1). doi: 10.2478/jhp-2022-0014

Figure 1. The European Principles of Care for Women and Girls with Inherited Bleeding Disorders [2]



Importantly, the Principles also provide a framework for driving new developments, such as EHC initiatives for strengthening registries, evolving care delivery and extending patient agency. Together with the evidence and discussions on which they are based, they can inform proposals and enable accelerated progress in the diagnosis and care of women and girls with bleeding disorders.

In developing the Principles, lessons have been learned from the successes and challenges of implementing the European Principles of Haemophilia Care published in 2008 [3]. Over the last 15 years, considerable advances have been made in establishing continuity of care, access to home treatment, better prophylaxis and better registries. However, some stakeholders still struggle to optimise partnerships that can deliver care and specialist services, and progress is still needed to make best use of research findings.

The introduction in 2021 of a new nomenclature to define haemophilia in women and girls by the Scientific and Standardization Committee of the International Society on Thrombosis and Haemostasis (ISTH) is also to be welcomed [4]. Based on personal bleeding history and baseline levels of factor VIII or factor IX, women and girls with levels of 40 IU/ml or above are recognised as symptomatic or asymptomatic carriers, and those with levels below 40 IU/ml are identified as having mild, moderate or severe haemophilia. In the literature and in much of the data that already exists, the distinction between a symptomatic carrier and a woman with mild haemophilia remains something of a grey area – carriers of haemophilia with normal factor levels but a history of bleeding and many women who clinically have mild haemophilia have been defined simply as 'carriers'. This legacy means we must assume that any reference to carriers of haemophilia – including during the conference and in reports from the conference – includes women with mild haemophilia. Unfortunately, we cannot be clear on how many.

In some areas WBD are already represented equally in registries, such as the diagnosis of those with rare bleeding disorders. In addition, the development of structures for research into bleeding disorders in women – involving both clinicians and patients –

can help move knowledge and care forward, with implications for longer term progress.

The Second European Conference on Women and Bleeding Disorders has built on the groundwork laid during the first meeting in 2019, extending knowledge and helping to create a network of women across Europe dedicated to sharing knowledge, best practice and support. Invited speakers shared a wealth of knowledge about the issues that matter most to WBD, and the valuable contributions of congress participants to discussions will fuel further ideas, developments and initiatives. The reports presented in this issue of *The Journal of Haemophilia Practice* capture key points and topics of discussion from some of the core sessions. We look forward to further progress in all of these areas and to welcoming delegates to the next European Conference on Women and Bleeding Disorders.

The EHC would like to thank everyone who has supported the Second European Conference on Women and Bleeding Disorders, including our generous sponsors CSL Behring, Roche, Takeda and Novo Nordisk. CSL Behring kindly donated the symposium *Cinderella: The glass slipper meets the glass ceiling*. Reports of the conference proceedings were donated by Haemnet Limited.

ACKNOWLEDGEMENTS

With thanks to the EAHAD Women and Bleeding Disorders Working Group and Dr Robert Klamroth, President of EAHAD, for permission to reproduce the European Principles of Care for Women and Girls with Inherited Bleedings Disorders infographic.

The authors have advised no interests that might be perceived as posing a conflict or bias.

This paper does not contain any studies involving human participants or animals performed by any of the authors.

ORCID

Naja Skouw-Rasmussen *https://orcid.org/0000-0002-7845-6230*

Declan Noone *https://orcid.org/0000-0003-2183-4277*

REFERENCES

1. Noone D, Skouw-Rasmussen N, Lavin M, van Galen KPM, Kadir RA. Barriers and challenges faced by women with congenital bleeding disorders in Europe: Results of a patient survey conducted by the European Haemophilia Consortium. *Haemophilia* 2019; 25(3): 468-474. doi: 10.1111/hae.13722.
2. van Galen K, Lavin M, Skouw-Rasmussen N et al. European principles of care for women and girls with inherited bleeding disorders. *Haemophilia* 2021; 27: 837-847. doi: 10.1111/hae.14379.
3. Colvin BT, Astermark J, Fischer K, et al. European principles of haemophilia care. *Haemophilia* 2008; 14(2): 361-74. doi: 10.1111/1365-2516.2007.01625.x.
4. van Galen KPM, d'Oiron R, James P, et al. A new hemophilia carrier nomenclature to define hemophilia in women and girls: Communication from the SSC of the ISTH. *J Thromb Haemost* 2021; 19(8): 1883-1887. doi: 10.1111/jth.15397

REPORTS FROM THE SECOND EUROPEAN CONFERENCE ON WOMEN AND BLEEDING DISORDERS

Edited by Declan Noone, President, European Haemophilia Consortium

- Noone D, d'Oiron R. Monitoring to improve quality of life in women with bleeding disorders. *J Haem Pract* 2022; 9(1). *https://doi.org/10.2478/jhp-2022-0015*
- Radhakrishnan S, d'Oiron R. Ageing and women with bleeding disorders. *J Haem Pract* 2022; 9(1). *https://doi.org/10.2478/jhp-2022-0016*
- Dougall A, Frenzel L. Focus on musculoskeletal health. *J Haem Pract* 2022; 9(1). *https://doi.org/10.2478/jhp-2022-0017*
- Pollard D, Khair K. The Cinderella Study: women's lived experience of bleeding disorders. *J Haem Pract* 2022; 9(1). *https://doi.org/10.2478/jhp-2022-0018*
- Grimberg E. Advocacy worldwide for women with bleeding disorders. *J Haem Pract* 2022; 9(1). *https://doi.org/10.2478/jhp-2022-0019*

HOW TO CITE THIS ARTICLE:

Skouw-Rasmussen N, Grimberg E, Noone D. The Second European Conference on Women and Bleeding Disorders, Basel, Switzerland, 10-12 May 2022. *J Haem Pract* 2022; 9(1): 118-120. *https://doi.org/10.2478/jhp-2022-0014*