

## WOMEN WITH BLEEDING DISORDERS

# The First European Conference on Women and Bleeding Disorders Frankfurt, Germany, 24-26 May 2019

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The European Haemophilia Consortium's (EHC) conference Women and Bleeding Disorders, held in May 2019, was the first such meeting dedicated entirely to discussing women's experience of living with a bleeding disorder, the activities of national member organisations (NMOs), and diagnosis and medical management. The conference welcomed almost 150 delegates from nearly 30 countries, including representatives from the European Association for Haemophilia and Allied Disorders (EAHAD) and the World Federation of Hemophilia (WFH).

The EHC has long sought to represent and serve women with bleeding disorders and others affected by a bleeding disorder. In 2015, it organised a pre-conference workshop entitled *Starting a European Conversation for Women with Bleeding Disorders* at its annual scientific conference in Belgrade, Serbia. The work of a group of dedicated volunteers from across Europe, has since enabled the EHC to build on this foundation to increase its focus on women, organising sessions specific to issues concerning women with

## PROCEEDINGS OF THE THE FIRST EUROPEAN CONFERENCE ON WOMEN AND BLEEDING DISORDERS

bleeding disorders at scientific conferences, youth debates and its annual Leadership Conference.

In 2017, the EHC created a Committee for Women and Bleeding Disorders to promote awareness, recognition, support, and education about and for women in the bleeding disorder community at a European level. The Committee organised a survey of women, NMOs and treatment centres to assess the prevalence and experience of bleeding disorders and the effectiveness of the support available. The survey showed that the needs of women with bleeding disorders are being neglected and provided the evidence on which the EHC can build a campaign to improve recognition and services for women with a bleeding disorder<sup>[1]</sup>.

The Committee invited EHC members to propose the topics to be addressed in this conference. The response was so great that it was a struggle to accommodate everything in the time available. However, the Conference Programming Committee ensured that the meeting covered a wide range of topics in plenary sessions, also providing time for delegates to talk about issues that affected them in Q&A and breakout sessions. The programme covered an overview of bleeding disorders affecting women,

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genetic transmission, gynaecological and non-gynaecological issues, managing monthly menses, the impact of bleeding disorders on quality of life, and tackling psychosocial issues. Breakout sessions focused on family planning, and support from NMOs and treatment centres.

The conference marked the premiere of the EHC's film *Women and Bleeding Disorders: Untold Stories*, directed by Goran Kapetanovic and made with financial support from Takeda. The film features women talking openly and honestly about living with a bleeding disorder, the impact of heavy periods on their lives and the implications for their future, including how it had affected their thinking about having a family. It also includes comment from the EHC's specialists on current management options and hopes for better improved treatment. The film will be a very strong advocacy tool and the EHC would like to thank all of the women who were brave enough to come in front of the camera to tell their story in a very intimate way. Accessible via the EHC website and YouTube, we are certain that this movie will help us raise awareness amongst a greater audience about issues faced by women with bleeding disorders<sup>[2]</sup>.

The EHC would like to thank everyone who has supported the First European Conference on Women and Bleeding Disorders. CSL Behring and Novo Nordisk sponsored the Conference; and CSL Behring kindly

donated the symposium on other gynaecological issues in women with bleeding disorders. These proceedings were donated by Haemnet.

We hope this conference has helped delegates gain more knowledge about women with bleeding disorders, and that it will provide the foundation on which to create a network of dedicated women across Europe who can share knowledge and best practice and – equally importantly – support each other.

## ACKNOWLEDGEMENTS

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

## REFERENCES

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