



MINI REPORT 1

Topic: Gender

To celebrate World Hemophilia Day 2017, and to mark this year's theme of women and girls affected by bleeding disorders, the WFH is publishing a Mini Report on gender, based on Annual Global Survey data. Lack of diagnosis and treatment for women and girls with bleeding disorders remains a challenge in our community¹. Highlighting gender data from the Annual Global Survey can help bring awareness to the issues facing women and girls.

Key Findings

- **65,284** women identified as having a bleeding disorder in the Report on the Annual Global Survey 2015²
- Annual Global Survey data from 1999 to 2015 demonstrates an increase in over **50,000** people identified with von Willebrand disease (VWD)

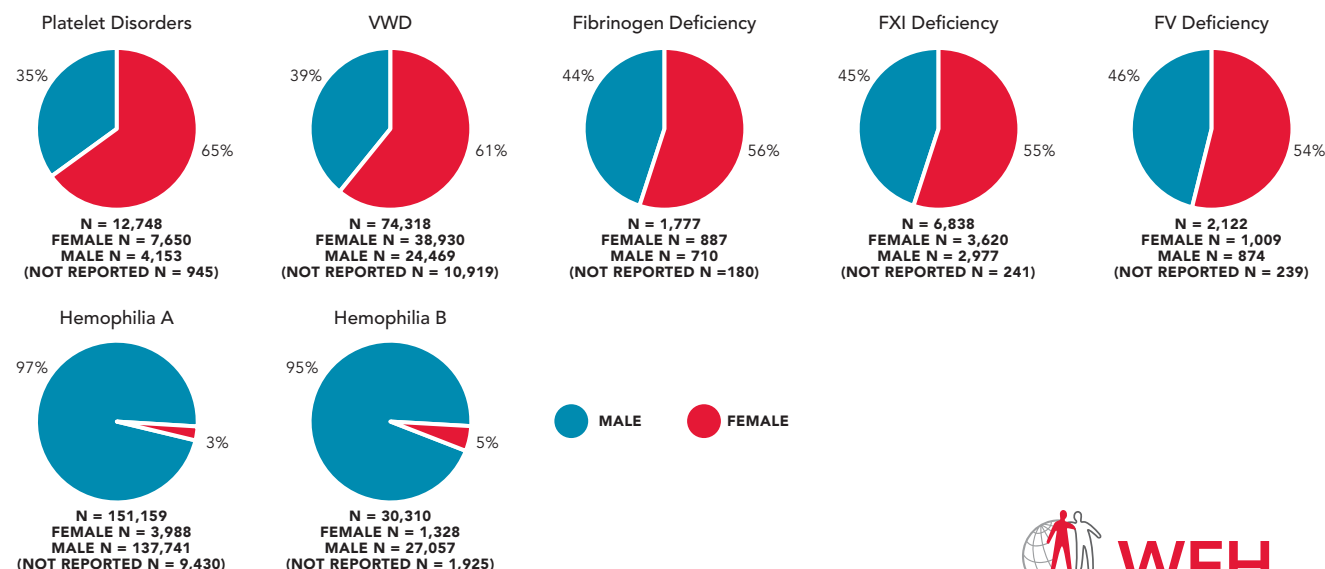
About Bleeding Disorders & Women

- A woman who has $\leq 40\%$ of the normal level of clotting factor (FVIII – hemophilia A, FIX – hemophilia B) is considered to be a person with hemophilia³
- The most common bleeding disorder for women and girls is VWD⁴

Gender Distribution: Report on the Annual Global Survey 2015

- The top five types of hereditary bleeding disorders with the largest proportion of women are: platelet disorders, VWD, Fibrinogen deficiency, FXI deficiency and FV deficiency (**Figure 1**)
- A gender breakdown for hemophilia A and B is shown, indicating that there are women who are affected by hemophilia

FIGURE 1: GENDER DISTRIBUTION OF BLEEDING DISORDERS



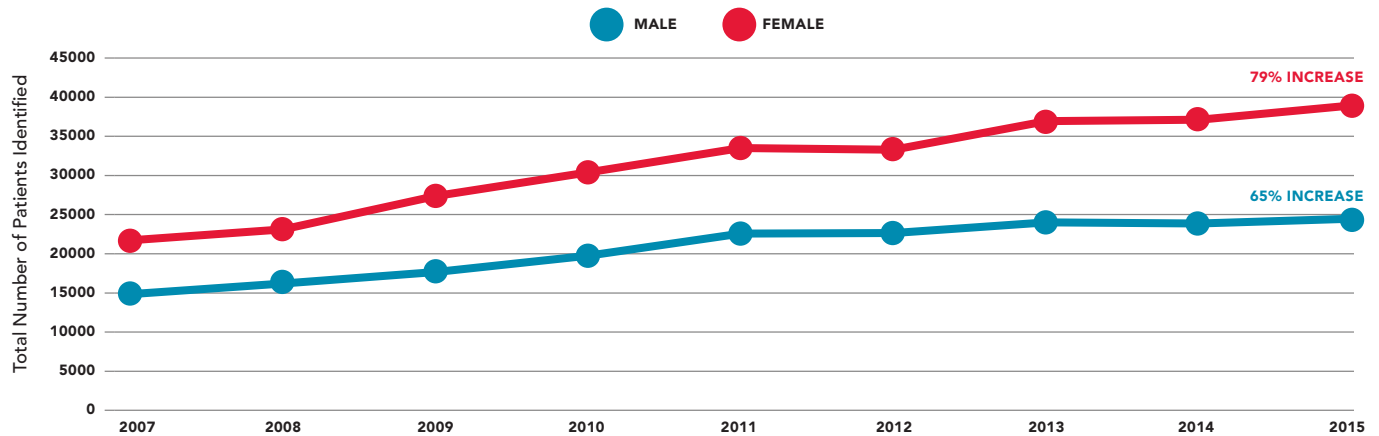
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Some countries are not able to report gender in the Annual Global Survey; therefore, these are reflected in the 'Not Reported' number.

Identification of VWD patients: Annual Global Survey 2007–2015

- The WFH Annual Global Survey began collecting data on gender distribution in 2007
- From 2007 to 2015, the reported number of women with VWD increased by 17,220 (Figure 2)
- During the 2007 to 2015 period, there was a 79% increase in the number of women identified with VWD

FIGURE 2: IDENTIFICATION OF VON WILLEBRAND DISEASE (VWD) PATIENTS



Evidence Based Advocacy

- Do you have advocacy programs in your country related to women and bleeding disorders? For example, outreach campaigns to increase diagnosis, efforts to build support with your Ministry of Health, or endeavours aimed at better informing healthcare professionals? **If so, use data to build your case.**
- To access the **Report on the Annual Global Survey 2015**, please visit: www1.wfh.org/publication/files/pdf-1669.pdf
- Additional data are available on the Annual Global Survey **Interactive Graphs**: www.wfh.org/en/resources/annual-global-survey

Self-BAT

If you are concerned about your bleeding symptoms, visit the Let's Talk Period website, which offers a self-administered bleeding assessment tool (Self-BAT): letstalkperiod.ca

For More Information

The Carriers and Women with Hemophilia eLearning Centre, on the WFH eLearning Platform elearning.wfh.org, is a one stop for easy access to information and resources on women and bleeding disorders. For webcasts on the subject, including an international panel discussion on VWD Outreach, visit the WFH Congress eLearning Centre.

Two particularly relevant publications in the Treatment of Hemophilia series are: Symptomatic Carriers of Hemophilia and Reproductive Health in Women with Bleeding Disorders.

Notes

Please feel free to contact us at globalsurvey@wfh.org with any questions or comments.

The WFH Annual Global Survey mini reports are developed under the supervision of the WFH Data & Demographics Committee.

References

1. James AH, Kouides PA, Abdul-Kadir R, Edlund M, Federici AB, Halimeh S et al. Von Willebrand disease and other bleeding disorders in women: consensus on diagnosis and management from an international expert panel. *Am J Obstet Gynecol* 2009; 201:12.e1-8.
2. World Federation of Hemophilia. *Report on the Annual Global Survey 2015*. Montreal, Canada: WFH, 2016.
3. World Federation of Hemophilia. *Carriers and Women with Hemophilia*. Montreal, Canada: WFH, 2012.
4. Centers for Disease Control and Prevention. *Bleeding Disorders in Women*. Atlanta, USA: CDC, 2016.



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