

Learn, Integrate, Collaborate
SPRING 2016

Educating Providers, Changing Lives

FWGBD is growing! Please note our new mailing address:

**Foundation for Women & Girls with Blood Disorders
PO Box 1358
Montclair, NJ 07042**

Join Us

Diagnosis in 16 Years: A Woman's Health, Public Health Crisis

Live Webinar
Thursday, May 19, 2016
12:00 PM - 1:00 PM EDT

Quality clinical services, specifically for women and girls with bleeding disorders, are key to accurate diagnosis, reducing complications and diminished quality of life, and improving women's health. Join the Hemophilia Federation of America's (HFA) Blood Sisterhood program in partnership with the Foundation for Women & Girls with Blood Disorders (FWGBD) for this important webinar. Learn how the FWGBD is working to ensure proper diagnosis, optimal management and treatment of women and girls with blood disorders through special initiatives with the 135 federally funded Hemophilia/Hemostasis and Thrombosis Treatment Centers (HTCs) across the country. This Webinar will provide an introduction and overview of WGBD Clinics of Excellence Initiative and Directory Project. The Directory identifies HTCs that offer services for women and girls, and those that have specific Women & Girls Bleeding Disorder Clinics.

Register for this free Webinar [HERE](#).

Hot Topic: Adolescent Thrombosis

Adolescent venous thromboembolism (VTE), or the clot formation in blood vessels in adolescents, is a serious condition that requires prompt recognition and optimal management to prevent mortality and long-term morbidity. Over the past 15 years, thromboembolic events (TEs) and the underlying inherited and acquired thrombophilic conditions have been increasingly recognized in teens at risk, with combined hormonal contraception constituting one of the most significant of these risk factors.



In an effort to provide education to providers on the recognition of thrombogenic risk factors for clot prevention and management, FWGBD hosted the following live webinar. We encourage you to view this important program, and to share it with a colleague or group who might also benefit from its information.

[Webinar: Adolescent Thrombosis: Etiology, Prophylaxis and the Role of Hormonal Therapy](#)

This Webinar will provide evidence-based, practical information on the complications of thromboembolism among female adolescents. It will also review the prevalence and presentation of risk factors predisposing adolescents to VTE and discuss prophylactic strategies. In particular, it will review the modern risk factor of increased screen time/reduced physical activity among adolescents and its relation to VTE. Lastly, it will inform medical providers on the role of hormonal therapy and the importance of a collaborative management by hematology and gynecology for thrombosis, thrombophilia and hormonal therapy in adolescent females. It originally aired on May 2, 2016.

View this Webinar [HERE](#)

READ

New Comprehensive Clinical Guidance on the Treatment of Venous Thromboembolism (VTE)

New detailed consensus guidance from fifty-eight leading experts on treating Venous Thromboembolism (VTE) from the *Journal of Thrombosis and Thrombolysis* is available free, online as open source material.

More information and a link to the Journal issue can be accessed [HERE](#)

Additional resources can be found in our [Library at fwgbd.org/library](http://fwgbd.org/library)

FWGBD wishes all nurses a very happy

National Nurses Week 2016

May 6 -12

Thank you for everything that you do.

In the Spotlight:

Canadian Health & Family von Willebrand Disease: Spreading Awareness



The key to preserving a high quality of life for patients with von Willebrand disease often begins with identifying its presence.

According to FWGBD Medical Advisory Committee member, Paula James, MD, of Queen's University, a diagnosis can be a positive thing, and recognition of the disease is often accompanied with optimism. "I'm always pleased when I make a new diagnosis of von Willebrand disease because we have so many effective treatments to offer patients."

Amongst James' primary goals as a hematologist, she emphasizes the importance of spreading awareness. To reach that goal, she and Canadian Health & Family have created a special program that utilizes, among other methods, two educational videos that may be shared with colleagues and patients.

Below are the links to the 4-minute and 1-minute programs.

4 Min: www.healthandfamily.ca/VonWillebrand

1 Min: www.healthandfamily.ca/show/von-willebrand-disease-spreading-awareness-2/

To learn more about the program, visit [Canadian Health & Family von Willebrand Program](#).



Save The Date:

September 19-20, 2016

2nd WGBD LAN In-Person Meeting

*Nationwide Children's Hospital
Columbus, OH*

Professionals who are members of our WGBD LAN, or who are working at or starting a Young Women's or Women's Bleeding Disorder Clinic will be invited to attend this meeting. This meeting is **by invitation only**; however, if you are interested, a small number of seats may be available. For more information, please e-mail kfunkhouser@fwgbd.org.

Read more about WGBD Clinics of Excellence:

Commentary by Barbara A. Konkle, MD

READ: Konkle, BA. Commentary: Progress toward meeting the needs of adolescent females with bleeding disorders. *Haemophilia*. 2016; 1-3. doi: 10.1111/hae.12870

Article by Ayesha Zia, MD, et al

READ: Zia A, et al. Developing a multidisciplinary Young Women's Blood Disorders Program: a single-centre approach with guidance for other centres. *Haemophilia*. 2016; 1-9. doi: 10.1111/hae.12836

Join the WGBD LAN

FWGBD's First Learning Action Network!

Learn how members of our WGBD LAN are making a difference in the care of women and girls across the country, and how you can join [HERE](#).

Contact

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FWGBD.org

Stay Connected



Our Mission:

FWGBD seeks to ensure that all women and girls with blood disorders are correctly diagnosed and optimally treated and managed at every life stage.