



***Learn, Integrate, Collaborate***  
**SUMMER 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 07042-1358**

## *New Service Launched:*

### *WGBD Clinics & Services of Excellence Directory*

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.

That is why FWGBD recently took the time to gather information about the availability and range of services - specifically devoted to the care of women and girls with bleeding and other blood disorders - that are offered at federally funded hemophilia/thrombosis treatment centers (HTCs) throughout the country. These services can be provided through a special, designated clinic for women/girls or through the general, regular HTC clinic serving all patients, male and female, together.

This is the **first-of-its-kind Directory**, signaling just where comprehensive services for women and/or girls with bleeding and other blood disorders can be found. We encourage you to access this free resource, and share it with others.



**Access this first-of-its-kind Directory [HERE](#)**

*This Directory was made possible through educational grants from the Hemophilia Alliance Foundation and Biogen.*

#### *WATCH*

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

Recently, the Hemophilia Federation of America's (HFA) Blood Sisterhood program partnered with the Foundation for Women & Girls with Blood Disorders (FWGBD) for an important webinar that introduced and provided an overview of the Foundation's WGBD Clinics of Excellence Initiative and the Directory Project. This program originally aired on May 19, 2016.

**View this Webinar [HERE](#)**

#### *READ*

## [Zia A, Rajpurkar M. Challenges of diagnosing and managing the adolescent with heavy menstrual bleeding.](#)

This recent article highlights the challenges clinicians face while diagnosing and managing adolescents with heavy periods and underlying bleeding disorders. It was published in the *Journal of Thrombosis Research* and can be accessed by clicking on the link below.

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

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

## *Congratulations to FWGBD's First RFA Recipient* *Promoting XXcellence in Women's Health: Optimal Management of Women and Girls with Blood Disorders*

Leslie Skeith, MD  
Thrombosis Fellow  
Ottawa, Ontario, Canada

The title of her winning application: ***Exploring the concept of a minimal clinically important difference in women with antiphospholipid syndrome and past pregnancy loss***

Learn more [HERE](#)

FWGBD will be at WFH in Orlando - will you?

**WFH 2016 World Congress**

July 24-28

Booth #37

*Stop our Booth to learn more about the Foundation and our upcoming programs.*

## *In the Spotlight:* **VTE in Adolescents**

**Did you know?** Several studies have documented that similar to infants, the rate of VTE in adolescents is higher compared to other children, and that adolescents are at the highest risk of developing VTE and have a higher proportion of recurrent VTE when compared to other children (Stein 2004; Ruffini 2009).

Approximately 95% of youth with adolescent VTE have one or more risk factors; most have more than one. Included among these are congenital or inherited abnormalities such as anatomic causes, autoimmune disorders, cancer and inherited thrombophilia, trauma, pregnancy and iron deficiency; and modifiable risk factors such as obesity, hormone therapy, and of recent interest, continuous video/computer gaming (Srivaths & Dietrich, 2016).

"Gamer's thrombosis" caused by venous stasis resulting from extended periods of sitting is an emerging threat for adolescents (Hayes, et al, 2013; Ng, et al, 2003; and Chew, 2006). Although information is scarce, a concern has been raised that continuous gaming may be a thrombotic risk factor of clinical significance (Srivaths & Dietrich, 2016).

Prompt evaluation and management of teenagers with VTE are needed, before it leads to complications such as stroke. However, recognizing VTE outside of the hospital setting can be very challenging and presents a significant clinical problem: most adverse outcomes and fatalities seem to occur in untreated patients because the thromboembolism goes unrecognized (Kline, et al, 2007).

That is why FWGBD recently hosted the Webinar: ***Adolescent Thrombosis Etiology, Prophylaxis***



Led by Drs. Jennifer Dietrich and Lakshmi Srivaths, this webinar provided evidence-based, practical information on the complications of thromboembolism among female adolescents. It also reviewed the prevalence and presentation of risk factors predisposing adolescents to VTE and discussed prophylactic strategies. Lastly, it provided information 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. This Webinar originally aired on May 2, 2016.

[View this Webinar](#)

## WGBD LAN News



*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 might be available. Respond soon. For more information, please e-mail [kfunkhouser@fwgbd.org](mailto: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

Kerry Funkhouser, EdD  
Director of Education  
[kfunkhouser@fwgbd.org](mailto:kfunkhouser@fwgbd.org)  
208.720.6430

[FWGBD.org](http://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.*

