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In Memoriam

It is with a heavy heart and great sadness that we announce that this will be Sandra Davy's last Social Work Corner column. Sandra Rebecca Davy passed away Wednesday, July 12, 2017. Sandra loved the bleeding disorder community and was beloved by all, especially the many that she helped individually. She was a wonderful social worker and friend, and we miss her very much.



Social Work Corner

by Sandra Davy, MSW

Greetings, Community!

On June 22 -23 2017, HFGF sponsored the Social Workers, Nursing Professionals, and Physical Therapist Conference in Orlando, FL. The purpose of the conference was to address the growing concerns of the Florida Hemophilia Treatment Centers (HTCs) Medical & Social Work professional staff members, and the needs of the population they serve.

Those concerns evolved into the topics listed below and resulted in discussion, education, and intervention methods, which they can use to strengthen their interactions with the Bleeding Disorders Community:

The requested education by the health care HTC professionals who attended the conference speaks to their motivation to meet the changing needs of their patients, and to the fact that patients should feel free to approach, engage, ask questions, share their concerns, and obtain information from their health care providers.

- Chronic Pain (musculoskeletal pain, temporomandibular disorder, headaches, widespread pain, joint/muscle/ligament pain) and mental health disorders, and how individuals with bleeding disorders can manage both.
- Deportation and its effect on physically abused/sexually violated, non-legal immigrants with bleeding disorders.
- Preparing teenagers with bleeding disorders for young adulthood in order that they are able to communicate their bleeding disorder diagnosis to others including health/school professionals; able to self-infuse; know the importance of having health insurance coverage, able to call their specialty pharmacy/home health care agency to order their factor/prescribed medication(s); and able to advocate for their health care needs.
- Educating the Hemophilia Treatment Center professionals on the reasons why patients may distrust medical professionals and how to engage and build trust with their patients.
- Guidelines for various sports and exercise (walking, stretching, weight bearing physical activities) for children & adults with bleeding disorders beginning in early childhood, adolescence, adulthood.

If you have questions, concerning the topics above, it would prove beneficial if you consider approaching your HTC hematologist, Nurse, and/or Social Worker and share your concerns.

Remember, knowledge is POWER!

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Mission
The mission of the Hemophilia Foundation of Greater Florida is dedicated to improving the quality of life for people with related bleeding disorders and their families through education, information and referral services, advocacy and research.

Disclaimer
The material provided in HFGF Connections is for your general information only. HFGF does not give medical advice or engage in the practice of medicine. The HFGF does not recommend particular treatments for specific individuals and recommends that you consult your physician or treatment center before pursuing any course of treatment.

Dear Friends,

Yay, it is summer! As far as I am concerned, it is the best time of the year.

Thank you to all that participated in the Woodstock Walk—what a fun day!!

So how did everyone enjoy our annual family program Independence Day at Ports of Call? We had such a good time celebrating everyone's bleeding disorder independence. Special shout out to Mike Rosenthal for creating and implementing the program.

I hope everyone enjoys their summer. Do not forget to mark your calendars for the Creepy Crawls in Jacksonville and Orlando.

Warmest Regards,

Fran



August 23-26 - NHF Annual meeting, Chicago

October 14 - Jacksonville Creepy Crawl 5k and walk, Nocatee

October 20-22-Family Retreat Weekend Camp Boggy Creek

October 22, 2017- Board of Directors Meeting, Orlando

October 23, 2017- Flight For Tomorrow Invitational Golf Tournament, Tampa

October 29, 2017- Orlando Creepy Crawl 5 K and Walk, Baldwin Park





F OR WOMEN ONLY . . . *Sort of*

By Joanna A. Davis, MD

The challenges identifying and medically managing carrier women are, finally, “hot” topics—for health care providers and families alike. We are increasingly aware of the variability in factor levels and symptoms. As discussed in an earlier newsletter, our HTC will be offering carrier women, between the ages of 12 and 40, the opportunity to undergo physical therapy evaluations and joint ultrasound examinations, because we now recognize that women with hemophilia may have unique joint issues.

But, women (including carriers) may have other bleeding disorders, which can negatively impact their life and health. Since many of these are genetic, it is not uncommon for women to not seek medical attention because their heavy periods, or easy bruising, or nosebleeds “run in the family” so they must be “normal.”

How many of our patients’ sisters/mothers/daughters/wives have been diagnosed with iron deficiency anemia, or “low iron?” It turns out that 15–25% of women with iron deficiency may actually have an undiagnosed bleeding disorder! And, not surprisingly, many health care providers, internists, pediatricians, family medicine and OB/GYN practitioners—are not aware of this implication in what is so often considered a “routine” female problem.

Bleeding disorders in women almost always affect what is called “reproductive bleeding”—menstruation, miscarriage and childbirth. It is logical (and easy) to “blame” iron deficiency on heavy menstrual flow, prescribe iron supplementation and move on. It is the responsibility of informed health care providers and patients/families to advocate further investigation to determine whether or not an underlying bleeding tendency is more directly responsible.

What are the bleeding disorders which can affect women? Remember, the formation of a clot requires normal quantities of normally functioning platelets (the sticky pieces of cells which form the first fragile clot) and a normal amount of functional clotting proteins. There are many proteins involved in clot formation besides VIII and IX.

The most common bleeding disorder in the world, affecting both men and women, is von Willebrand disease. People with vWD either make a less-than-normal amount of the von Willebrand protein or they make defective von Willebrand protein. People can be born unable to man-

ufacture a normal amount of any clotting protein—we have many patients who are deficient in clotting factor 1 (fibrinogen), V, or VII, or X, or XI.

- Carrier women may have lower-than-normal levels of factors 8VIII or IX.
- Some people have platelets which don’t stick well—the platelets are missing some critical proteins.
- Some people don’t manufacture sufficient platelets to form that first delicate clot.
- Some people break down the clots they make too rapidly.
- Some people are sensitive to aspirin or Advil, which may actually interfere with how their platelets stick together.

Rather than offer a textbook listing of symptoms, specific treatments, etc., it is important for a woman to recognize the possible “warning signs” for excessive menstrual bleeding, so that the discussion for further workup can be had with her health care provider:

- Periods routinely lasting for more than seven days
- “Flooding” or bleeding through pads/tampons in two hours or less for several days of each period (changing pad/tampon every 1- 2 hours because they are soaked)
- History of iron deficiency anemia
- Family history of a bleeding disorder
- Personal or family history of excessive bleeding with surgery, trauma, dental extraction, childbirth
- Personal or family history of blood transfusion as management of heavy menstrual bleeding or postpartum bleeding
- Family history of women who underwent early hysterectomy to control heavy menstrual bleeding or postpartum hemorrhage

There are many possible explanations for women who are experiencing heavy periods, recurrent nosebleeds, easy bruising. However, it is absolutely necessary to include a possible underlying bleeding disorder in the list of potential diagnoses, and to include the hematologist—preferably at an HTC—in the evaluation process!

Dr. Joanna A. Davis is the medical director of the Comprehensive Pediatric Hemophilia Treatment Center at the University of Miami Miller School of Medicine



SAVE THE DATE



For some **SPOOKY** doings in October!

You can help raise funds for the HFGF and have a lot of fun at the same time.

Choose your walk:

[Jacksonville 5K Creepy Crawl and Vampire Mile](#)
Saturday, Oct. 14 at Nocatee

[Orlando Creepy Crawl Walk and 5K](#)
Sunday, Oct. 29 at Harbor Park on Lake Baldwin

www.hemophiliaflorida.org/jacksonville.html

www.hemophiliaflorida.org/orlando.html



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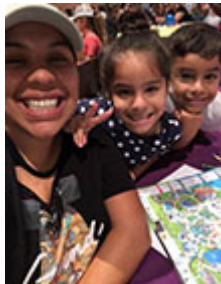
Wonderful Day at Seaworld

Five hundred people in the bleeding disorders community attended the program "Independence Day" on Saturday, June 10. The speaker was Michael Rosenthal, recipient of eight awards of excellence from the NHF for developing and implementing innovative programming, and former executive director of the Arizona Hemophilia Association, and former national director of the World Federation of Hemophilia, US. Afterwards, the attendees were able to enjoy the park.



HFGF would especially like to thank our sponsors for making the event possible:

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REGISTER NOW!

for the

Flight For Tomorrow

<http://www.hemophiliaflorida.org/golf-tournament.html>

Invitational Golf Tournament

October 23, 2017
Avila Golf & Country Club



Our Mission

The Hemophilia Foundation of Greater Florida, a chapter of the National Hemophilia Foundation, has been serving people with bleeding disorders since 1996. We are helping the bleeding disorders community improve their quality of life by offering programs and services to support healthier and more independent lives.



Corporate Matching

Did you know that many companies will match your tax-deductible donation to the Hemophilia Foundation of Greater Florida? [Click here](#) to check out our list to see if your company has a matching program!



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