

FACTOR NOTES

BROUGHT TO YOU BY THE SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

A LITTLE EXERCISE & A LOT OF IMPACT

THE 5K FOR BLEEDING DISORDER AWARENESS WALK RUN WILL BE HELD AT THE RICE FIELD BIKE PATH IN MIAMISBURG ON SEPTEMBER 17TH.

It is the 12th year for this incredible event. If you've never participated in a SWOHF fundraiser, let this be your year. You can participate as an individual, family, or a group... work, church, sports team. What better way to boost morale and make an impact for the Bleeding Disorders Community.

Generally, it is a beautiful day in September. Picture yourself walking or running on the beautiful banks of the Great Miami River. The birds are singing, and the sky is blue. What more do you need to enjoy the day? Registration is only \$25 and it is a BOGO...buy one get one through September 7th. Everyone loves a BOGO. Please scan the QR code below to register now.

We can't wait to see you in September!

BUY ONE
GET ONE
FREE

2022
ISSUE #2

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**RICE FIELD BIKE PATH
MIAMISBURG, OH
SEPTEMBER 17**

\$25, BOGO THROUGH 9/7!

REGISTER NOW!!!



**SOUTHWESTERN OHIO
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Moraine, OH 45439

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2022 EVENTS

JULY

SWOHF Family Fest
Friday-Sunday, July 8-10

NEW VENUE! Scene 75
Dayton, OH

Educational Fitness Presentation by John Huddelston
(Endurance Athlete with Hemophilia, courtesy of
Cottrill's Pharmacy), Industry Partner Displays,
July 9th Dayton Dragons Game



AUGUST

FAMOHIO Annual Conference

Friday-Sunday, August 5-7
Columbus Marriott
Columbus, OH

NHF Bleeding Disorders Conference

Thursday-Saturday, August 25-27
Houston, TX

**Registration required
for all events.**

Check swohf.org
or the newsletter
for updates!

SEPTEMBER

**SWOHF Bleeding Disorders
Awareness 5K**

Saturday, September 17
Rice Field
Miamisburg, OH



OCTOBER

SWOHF Fall Outing

Sunday, October 9
Young's Dairy
Yellow Springs, OH



NOVEMBER

SWOHF Women's Day Together

Saturday, November 12
The Golden Lamb Inn
Lebanon, OH



APPLY NOW

The Brad Miller Memorial Scholarship has been created to commemorate and remember an exceptional young man from the bleeding disorder community. Brad was born with severe hemophilia in 1979, a time when hemophilia treatment was less refined and many treatment products were ultimately found to be unsafe. These and other life issues contributed to the many challenges experienced by this scholarship's namesake. Throughout his 29 years, Brad held his head high and did his very best to live each day fully. Brad's immediate and extended family members supported him during his short life and continue to be active volunteers and mentors for the bleeding disorder community. Through this scholarship, Brad and his family's spirit of living and dedication to giving will continue to honor Brad and the entire bleeding disorder community for many years to come.

The SWOHF board and the members of the scholarship committee acknowledge the many challenges students face during their journey to complete a post-secondary educational program or beyond. It is hoped that the financial assistance provided by the Brad Miller Memorial Scholarship of \$2,000.00 will help recipients continue their quest for knowledge and the attainment of their dreams.

The Brad Miller Memorial Scholarship is open to any person with a bleeding disorder diagnosis, i.e., hemophilia, von Willebrand disease or other inherited bleeding disorders, who receive treatment at Dayton Children's Hemostasis and Thrombosis Center. The applicant must be seeking post-

secondary education at a university/college or technical school or be enrolled in a graduate school program.

The scholarship application and supporting documents must be submitted by July 13, 2022. The decision by the scholarship committee will be announced by July 31, 2022. Payment will be made directly to the student's university/college or technical school.



For more information about the application process, check our website for a list of requirements and to download the application form. The completed application and all supporting documentation should be submitted via email to joy@swohf.org by July 13, 2022.



A promotional graphic for the FAMOHIO CONFERENCE. It features several cartoon red blood drops with faces and arms. One large drop in the center has a name tag that says 'HELLO, I'M So happy to see you!'. Another drop to its right has a name tag that says 'HELLO, I'M DITTO!'. In the background, there is a map of Ohio with the text 'FAMOHIO' above it. To the right, a red arrow points to a QR code with the text 'REGISTER NOW!!!'. At the bottom, the text reads 'Back in person & better than ever!' followed by 'FAMOHIO CONFERENCE August 5th - 7th 2022'. A small red drop with the number '3' is in the bottom right corner.



WHAT TO EXPECT IN A CLINICAL TRIAL

The research team at Dayton Children's Hemostasis and Thrombosis Center (HTC) conducts many clinical trials. The principal investigator (Dr. Jordan Wright) and the study coordinators (Beth Linegang and Melissa Tucker) discuss which patients are appropriate for the study and could ultimately become study participants. When searching for patients who might qualify for research studies, the team evaluates the studies inclusion and exclusion criteria.

Inclusion criteria are the characteristics of the patient which would allow them to be a part of the study. Some examples are:

- one must have severe hemophilia
- > 65 kg in weight
- male
- currently on prophylactic treatment

Exclusion criteria are the characteristics of the patient that would not allow them to be a part of the study. Some examples of exclusion criteria are:

- < age 12
- history of heart disease
- history of a stroke

After the team reviews the inclusion and exclusion criteria and determines who may be eligible the team contacts patients to see if they would like to be enrolled in a clinical study. To enroll, a patient will be asked to sign an informed consent form (ICF).

An ICF is a document that reviews one's personal risk of being in the study and has eight basic elements:

DESCRIPTION OF THE TRIAL

This section of the ICF explains that the clinical trial involves research, and the primary purpose of one's participation is to be a part of research. Often studies conducted at the HTC are to evaluate the safety and effectiveness of a treatment. The description includes a discussion of how the research differs from one's current treatment. The description also discusses possible consequences to one's participation. It outlines the visits, what is expected of the patient at each step of the trial, and what happens at each visit. It must also discuss if there is any long term follow up.

RISKS AND DISCOMFORTS

This section of the ICF covers any risks or discomforts of tests, including those that carry significant risk. It will also state that there may be risks that cannot be predicted that might occur in the future. Some examples are; pain may occur with a lab draw, or that the drug might have unknown effects on an unborn fetus. It is important that one clearly understand the risks to participating.

BENEFITS

This section of the ICF identifies potential benefits to not only the patient but also to future patients with the disease or condition.

ALTERNATIVE PROCEDURES OR TREATMENTS

This section of the ICF must discuss appropriate treatment alternatives to entering the clinical trial that might be helpful for the subject. It also should discuss that participating in this clinical trial may keep patients from being eligible for another clinical trial.

CONFIDENTIALITY

This section of the ICF describes how the study will use and protect one's personal information. It describes how privacy will be maintained and where records will be stored. It will also detail who will be able to gain access to these confidential records.

COMPENSATION AND MEDICAL TREATMENT IN CASE OF AN INJURY

This section of the ICF covers the organization that is responsible for compensation and medical treatment should injury to a person occur as a result of the study.

CONTACTS FOR THE STUDY

This section of the ICF describes the contact persons for the study. This is the number a patient can call for any questions or concerns 24 hours/day. If this information changes during the study, study participants must be updated with new numbers.

VOLUNTARY PARTICIPATION

This portion of the ICF includes a statement that the patient understands that participation is voluntary. There is no penalty for discontinuing participation in the study at any time.

Once the ICF is reviewed and signed by the patient and the investigator and the signatures witnessed by a third person, the patient will begin time as a study participant. Depending on the study, the design of the visits will vary. Usually, the visit will include the coordinator asking questions about the risks and benefits, exclusion/inclusion criteria, lab work, and administration of an intervention such as a survey or medication. Multiple clinic visits are usually included in the study, and all costs related to those visits are covered by the study sponsor. Long term follow up may be required of the study, if not the study participant will resume regularly scheduled visits and treatment.

WHO RUNS THE STUDY?

The research team at Dayton Children's Hemostasis and Thrombosis Center consists of investigators and coordinators. The sub-investigators are hematology physicians with Dr. Wright as the principal investigator. The coordinators are research nurses in the HTC. The people in these positions may change depending on which HTC one is visiting; however, all have specialized training on the research process.

Members of the research team are always willing to discuss research opportunities at any time during one's regularly scheduled appointments or by phone.

References

July 14, 2014 — FDA US Food and Drug Administration
www.fda.gov/regulatory-information/search-fda-guidance-documents/informed-consent#description

CASINO NIGHT



WHERE WERE YOU ON MAY 6TH?

We were at the Dayton Woman's Club enjoying a wonderful evening of gaming, appetizers, and entertainment. It was our first Evening Out event post COVID. Thanks to our Industry sponsors for providing funding, and our wonderful guests for supporting us. We were able to raise over \$11,000!!! Save the Date Casino Night 2023 will be held May 5th. Put it on your calendar now. **You won't want to miss it!**





MARK YOUR CALENDARS!
CASINO NIGHT 2023
FRIDAY, MAY 5



CASINO NIGHT

Thank you



Dessert Table Sponsor:

CSL Behring



Industry Partner Sponsors



Silent Auction & Prize Donors:

Arrow Wine & Spirits
Bagger Dave's
Bangs Salon—Madison
Beavercreek Golf Club
Butler Heating & Air Conditioning
CoCo's Bistro
Company 7 BBQ
Dayton Family Massage
Don Patron's Mexican Grill
Environmental Doctor
Eye 1 Unique Eyeware
Flying Pizza
Geez Grill & Pub
GiGi's Cupcakes

Goldshot, Lamb & Hobbs Inc.
Hollywood Gaming
Jersey Mike's
Jimmie's Ladder 11
Katie's Hallmark
King's Island
Maraluna/Oakwood
Meadowlark Restaurant
Menard's
Miami Valley Wine & Liquor
Miya's Hair Nails
Neon Theatre
Partial to Pie

Pine Club
Ray's DriveThru
Roosters
Scene 75
Scentsy—Madison
Scramblers
Sky Asian Cuisine
Stockslager's Greenhouse
Submarine House
Target (Huber Heights)
The Golden Lamb
The Spicy Olive
Yankee Trace Golf
Young's Dairy

Jenny Bostater
Carolyn & Steve Brown
Lindsay Carlson
Kay Clark
Cheryl Coffey
Denise Eder
Lisa Geers
Sandy Hibner
Nick Lamb
Joy Linder
Dick Miller
Harlan Miller
Dena Shepard

A **ONCE-WEEKLY** TREATMENT OPTION FOR HEMOPHILIA B.



HOW DOES
THIS FACTOR IN?

To find out about a prescription
option, talk to your doctor or visit
[OnceWeeklyForHemophiliaB.com](https://www.OnceWeeklyForHemophiliaB.com)

SERVICE DOGS

WHAT YOU NEED TO KNOW

September will be here soon and it is National Service Dog Month, a time set aside to raise awareness about these animals and the service they provide people in their care. Service dogs include guide dogs for the blind, hearing dogs for the deaf and mobility assistance dogs.

Fortunately, both federal and state laws offer protections for the use of service animals in various situations, including places of public accommodation, like restaurants. However, before a person who needs a service animal can have any of the legal protections, he or she must have a disability, which is defined by each of the pertinent laws.

Many people don't realize there are actually **rules of etiquette** when you're in the presence of a service dog. There are helpful articles online you can reference for more information – check out “8 Do's and Don'ts for Behavior Around a Service Dog Team” at healthypets.mercola.com, as well as “7 Guide & Service Dog Do's and Don'ts” on parade.com

The general rule for service dogs is this: DON'T TOUCH OR DISTRACT THEM.

Here's some info from a website that is a great resource to check out about service dogs in the State of Ohio -- disabilityrightsohio.org/service-animals

What is the definition of a service animal under Title III of the ADA (Americans with Disabilities Act)?

A service animal is a working animal, **not a pet**. Regulations under Title III of the ADA define a service animal as any dog that is individually trained to do work or perform tasks for the benefit of an individual with a disability.

Are emotional support, therapy, comfort, or companion animals considered service animals under the ADA?

No. These terms are used to describe animals that provide comfort just by being with a person. Because they have not been trained to perform a specific job or task, they do not qualify as service animals under the ADA.

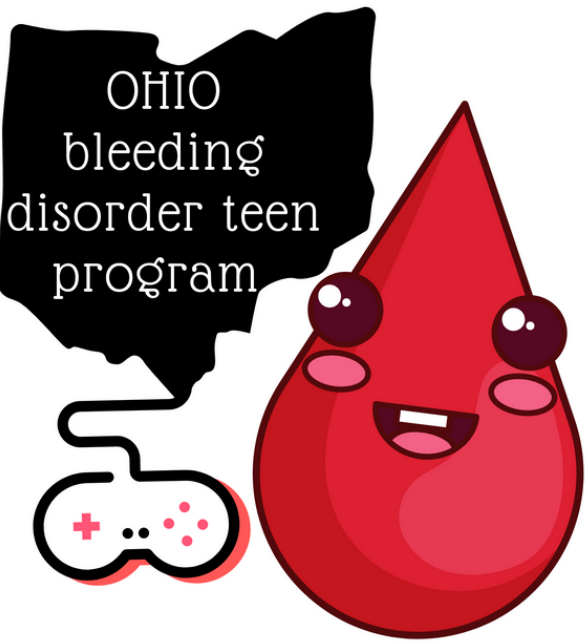
What are the responsibilities of a person who uses a service animal in a place of public accommodation?

The service dog's handler must maintain control of the animal, and the animal must have a harness, leash or other tether. However, if a disability prevents the person from using those or if a tether would interfere with the performance of the dog's job, then the dog's owner must maintain control through other effective means, such as voice control or signals.

At SWOHF events, we value the special assistance that the service dog provides the owner; equally important is the safety of all individuals in attendance. **Children should never approach a service dog.** If you are at a SWOHF community event/program and are concerned about a service dog, please notify SWOHF Staff or Board members immediately. A service dog's owner may be asked to remove the dog if it is out of control and the owner does not take effective action to control it or if the animal is not housebroken. If properly excluded for one of these reasons, the individual would be asked to leave the event and could return without the service animal.

In some states, there are laws that make it a misdemeanor to represent an untrained dog as a service animal and fines up to \$500 for an incident. Because there is currently no certification or official national registry of legitimate service dogs, there is no way to verify whether a dog has undergone rigorous training to become a service animal. However, trained service dogs don't go off-leash, bark, knock things off shelves, jump on people, play or fight with other dogs, or grab food off tables, trainers say.





October 8th & 9th at Maumee Bay

This program is open to OHIO teens age 13 to 17 with a bleeding disorder and siblings in the same age group living in the same household.

Sponsored by:



SAVE THE DATE!



**CENTRAL OHIO CHAPTER
NATIONAL HEMOPHILIA FOUNDATION**

Questions? Contact tanya@nohf.org



JOY@SWOHF.ORG



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SWOHF
SOUTHWESTERN OHIO
HEMOPHILIA FOUNDATION

CONTACT US

WE WANT TO HEAR FROM YOU!

MISSION STATEMENT

SWOHF helps improve the quality of life for those affected by hemophilia, von Willebrand disease, and other bleeding disorders by providing support education, networking, advocacy, and services to individuals, their families and the community.

EXECUTIVE DIRECTOR

Joy Linder

DISCLAIMER

The material provided in Factor Notes is for your general information only. SWOHF does not give medical advice or engage in the practice of medicine. SWOHF under no circumstances recommends particular treatment for specific individuals, and in all cases recommends that you consult your physician or treatment center before pursuing any course of treatment.

Southwestern Ohio Hemophilia Foundation

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