

FACTOR NOTES

BROUGHT TO YOU BY THE SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

CROSS THE FINISH LINE WITH US!

AT THE BDA-5K — SAVE THE DATE **SEPTEMBER 16, 2023**

Please join us for the Southwestern Ohio Foundation on Saturday September 18th for our 13th Annual Walk/Run for Bleeding Disorder Awareness. Registration is only \$25 per person and includes a bib, timed finish, and T-shirt. We would love for you to come be a part of making a difference in the lives of those living with blood disorders like Hemophilia and von Willebrand's disease as we walk or run our way to victory!

Cascade Hemophilia Consortium is once again sponsoring a BOGO! For every person signed up, another participates for free. This is an early registration benefit so don't forget to sign up by September 6th. Once again, the event will be held at Rice Field Bike Path in Miamisburg. Registration begins at 9:00 am.

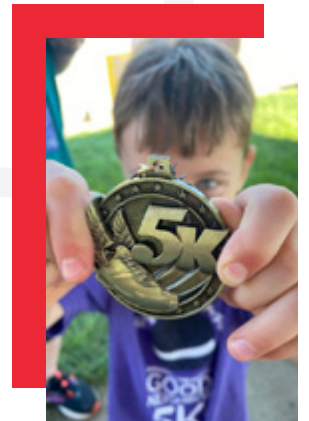
We need you! Consider gathering a team of friends, family, coworkers. Your support makes a difference in the lives of others. Believe there is Good in the World!

REGISTER NOW!!!



2023 ISSUE #2

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SAVE THE DATE

FAMOHIO FAMILY EDUCATION WEEKEND

AUGUST
4 - 6, 2023

REGISTRATION AND INFO WILL BE AVAILABLE IN SPRING.
STAY TUNED FOR MORE DETAILS!

2023 EVENTS

JULY

Family Fest

July 7-8

Scene 75 & Dayton Dragons



AUGUST

FamOhio

August 4-6

Columbus, OH

NHF Bleeding Disorders Conference

August 17-20

National Harbor, MD

TRAVEL SCHOLARSHIPS AVAILABLE



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Registration required for all events.

Check swohf.org or the newsletter for updates!

SEPTEMBER

Bleeding Disorders Awareness 5K

September 16

Rice Field

Miamisburg, OH



OCTOBER

Fall Outing

October 8

Young's Dairy

Yellow Springs, OH



NOVEMBER

Women's Day

November 11

The Golden Lamb Inn

Lebanon, OH



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Explore Head-to-Head Pharmacokinetic (PK) Study Data

See half-life, clearance, and other PK data from the crossover study comparing Kovaltry® and Advate®.

Visit [Kovaltry-us.com](https://www.kovaltry-us.com) to find out more.

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Antihemophilic Factor (Recombinant)

IT IS TIME TO RE-ENROLL FOR THE OHIO BLEEDING DISORDERS DENTAL PROGRAM!



This program is administered by the Northern Ohio Hemophilia Foundation (NOHF) on behalf of the Ohio bleeding disorders network of treatment centers and chapters.

To maintain coverage on the Dental program you must meet these guidelines:

- Return the completed Delta Dental Enrollment (contact SWOHF for Forms)
- Stay current with your comprehensive care outlined by your HTC.
- Each enrollee with a bleeding disorder must receive at least one cleaning per year.
- Provide feedback through the survey provided with forms.
- Return all forms and pay annual enrollment fee by the **deadline of July 15, 2023.**

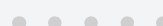
Your coverage will continue from July 1, 2023, through June 30, 2024. If you no longer need or want services throughout the year, please notify Randi Clites at randi@nohf.org



Special thanks to Cascade hemophilia Consortium for providing the funds to offer Ohio's patients access through the Delta Dental Plan. Your coverage includes twice yearly cleanings and also provides 100% payment for covered services provided by a Delta Dental network dentist after \$100 deductible due to the dentist of your choice up to a maximum of \$1250 per enrollee.

It is vitally important that you take advantage of your twice-yearly cleanings and checkup benefits. Due to increasing premium rates NOHF will closely monitor the utilization of those who are on the program and enrollees who are not using their benefits will be removed from the plan.

Applications are available on our website swohf.org under Resources or contact the SWOHF Office via email: director@swohf.org



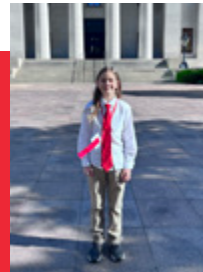
OBDC STATEHOUSE DAY

The Ohio Bleeding Disorders Council returned to an in-person event for the 2023 Statehouse Day May 8-9th.

OBDC hosted about twenty families in Columbus to meet with their elected officials. This year we had something to celebrate. House Bill 185 in the 134th General Assembly passed recognizing March as Bleeding Disorders Awareness Month. Ohio will officially

recognize March of 2024 as the first bleeding disorders awareness month. Please keep a close eye out next year for ways you can participate in activities around the state.

During the event, families met with about 30 lawmakers in their offices and hosted another 60 members and staff at lunch to share their bleeding disorders story and advocate for issues impacting our community. Issues addressed this year were supporting an age increase of the CMH treatment program up to 26 in the state budget and banning the use of copay accumulators on health insurance plan designs.



If you missed Statehouse Day, but would like to meet with your elected officials please reach out to Randi Clites, OBDC State Policy Director randi@nohf.org to schedule an in-district meeting this summer.

KROGER

Shop at Kroger,
Support SWOHF!

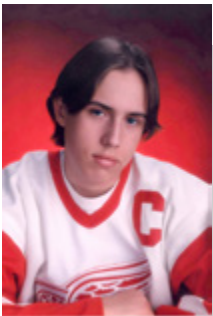
Did you know you can support our SWOHF community just by shopping at Kroger? It's easy when you enroll in **Kroger Community Rewards!** To get started, sign up at krogercommunityrewards.com with your Kroger Plus Card and enter our number **#78558** as your organization. Once you've enrolled, you'll earn rewards for SWOHF every time you shop at Kroger and use your Plus Card!

Kroger is committed to helping our communities grow and prosper. Year after year, local schools, churches and other nonprofit organizations earn millions of dollars through Kroger.



BRAD MILLER MEMORIAL SCHOLARSHIP

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.

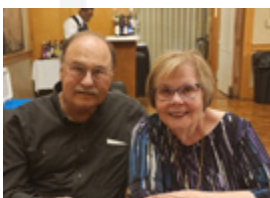
The scholarship application and supporting documents must be submitted by July 10, 2023. The decision by the scholarship committee will be announced by July 31, 2023. Payment will be made directly to the student's university/college or technical school.

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 10, 2023.

CASINO NIGHT

Casino Night was a wonderful success. We raised the fun and the funds...over \$7000! Thanks to everyone who came out and a big shout out to our sponsors CSL Behring, HEMA Biologics, Novo Nordisk, Bayer, and Cascade Hemophilia Consortium.

Save the Date May 3, 2024!



WHAT IS BD SUMHAC?



BD SUMHAC

Bleeding Disorders Substance Use & Mental Health Access Coalition

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Did You Know?

The **Bleeding Disorder Substance Use and Mental Health Access Coalition** (BD SUMHAC) was established in January of 2022. The Coalition grew from the realization of problems experienced by individuals with bleeding disorders who needed in-patient addiction and/or mental health services. Historically, many residential substances use disorder (SUD) facilities have denied admittance to such individuals. The basis for the denials most often has been the use of self-administered, intravenous medication such as factor replacement. This ruling can have very serious or even fatal outcomes for those with bleeding disorders in need of acute help with addiction and/or mental health treatment.

Results of a national survey of hemophilia treatment centers (HTC) providers demonstrated that most attempts to place individuals with a bleeding disorder at a residential addiction treatment facility were met with failure. However, there have been some placements and those who secured success are willing to share their practice, thus a document that provides best practices has been developed. This document is comprehensive and shares what to do when, additional things to consider prior to making a referral along with the actual referral process, and what to do in the event of a denial.

Best Practices for Accessing Residential Substance Use Disorder Treatment for Individuals with Bleeding Disorders is a product of the BD SUMHAC. Their mission is to advocate for access to appropriate SUD and mental health (MH) treatment facilities for all individuals with bleeding disorders. The Coalition plans to develop a similar document centered on access to Mental Health facilities. These documents will be housed in the Provider's Toolkit.

The Coalition is very eager to collect as much information as possible relevant to denials for residential SUD treatment, so that they can continue to refine best practices and enhance support for individuals with bleeding disorders. Contact information for reporting these denials can be found in the document.

BD SUMHAC was formed via a partnership between the New England Hemophilia Association (NEHA), Hemophilia Federation of American (HFA), the National Hemophilia Foundation (NHF), HTC providers, and bleeding disorder community members. Sponsoring organizations include NHF, NEHA, and the HTC at Rush University Medical Center. To continue this mission, funds have been requested by the BD SUMHAC. The board of the Southwestern Ohio Hemophilia Foundation recently voted to support this initiative by donating to BD SUMHAC at the "Friends" level.

A personal account exemplifying the extreme need for this initiative can be found at:

Coalition Advocates for Substance Use Disorder/Behavioral Health Services for Patients With Bleeding Disorders | New England Hemophilia Association

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REFERENCES

Coalition Advocates for Substance Use Disorder/Behavioral Health Services for Patients With Bleeding Disorders | New England Hemophilia Association

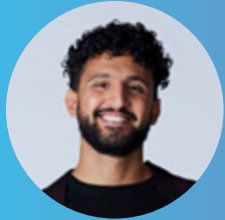
New Document to Help Residential Substance Use Disorder Placement for Individuals with Bleeding Disorders | National Hemophilia Foundation



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laith.elkurd@sanofi.com
857-270-1962



Learn more at
ALTUVIIIIO.com or by
scanning the QR code

ALTUVIIIIO™ 
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Fc-VWF-XTEN Fusion Protein-ehtl

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FAMILY FEST

JULY 7 & 8, 2023

The weekend begins at Scene 75 on Friday starting at 4:00 pm with industry sponsor exhibits, dinner and a lively educational program featuring Tim Ringgold, renowned speaker and musician who will present an informative and lively program that you will most certainly enjoy.



“Reach for Music to Reduce Stress Fast”

Be prepared to sing and shake along to the music and casually learn to melt stress away! Appropriate for children and adults.

SWOHF will provide game cards for all to enjoy a full night of interactive play at **Scene 75**.

We will also have **Dayton Dragons** tickets available for Saturday, July 8, at 7:00 pm

The cost is \$5 per person. Please contact the SWOHF Office at 937-298-8000 if you require assistance; scholarships are available.

Register online at www.swohf.org or scan the QR code.

Registration deadline for a T-shirt is 6/24/23.

Special thanks to HFA for providing an Education Grant for this family program!



2023 GETTIN' IN THE GAMESM

**October 6 - October 8
Henderson, Nevada**

Each chapter may nominate two individuals to attend: Baseball, basketball, golf, or swimming.



If you are interested in being nominated by SWOHF to attend this year's Gettin' in the Game Program, watch your email for more information and application form. If you have questions, please email director@swohf.org or call 937-298-8000 during office hours.

After Board review of all applications, SWOHF will nominate two individuals only (with one parent per child). Travel arrangements will be made through CSL Behring Travel. All eligible travel expenses and meals during the conference will be paid by CSL Behring.

**DEADLINE FOR APPLICATIONS IS
JULY 17, 2023.**

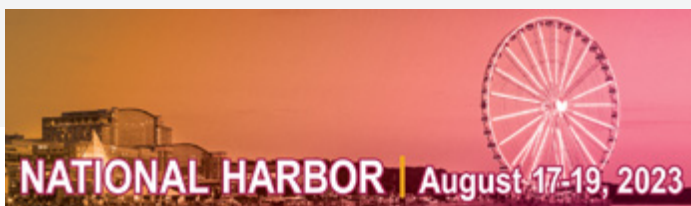
TRAVEL SCHOLARSHIPS AVAILABLE



The 75th Annual Bleeding Disorders Conference (BDC) will take place from August 17 to 19, 2023 at the Gaylord National Resort & Convention Center in National Harbor, Maryland. Located on the historic Potomac River and within short distance of national landmarks in nearby Washington, DC, this will be the perfect setting for BDC 2023 as we mark our 75th anniversary and embark on a new phase for our organization and bleeding disorders community.

This 75th anniversary edition of the Bleeding Disorders Conference will be a momentous celebration for our community. Join NHF for three days of educational sessions, exploring the exhibit hall, and spending time with the incredible bleeding disorders community.

Travel scholarships are available - see more information online to complete an application. If you have questions, contact us in the SWOHF Office 937-298-8000 during business hours.



MEDICAL IDs

In collaboration with Dayton Children's HTC, SWOHF has recently switched to a new provider for our Medical ID's. We are happy to announce our partnership with American Medical ID. They offer a great variety of quality products at a discount to Chapters. Additionally, their Customer Service is exceptional, their shipping is fast and their prices are significantly less than MedicAlert (our previous supplier).

Free products are included with every order: An emergency medical ID card, a small ID charm and an exclusive engraved rectangular "InCase" phone ID that easily attaches to your cellphone case or any flat object, such as a suitcase, briefcase or laptop.

SWOHF is grateful for grant funding and donations that facilitate these purchases on behalf of our Greater Dayton Bleeding Disorders Community. So when you go to the HTC for your next visit, you can view sample products available and complete a form to request a new bracelet or necklace according to Chapter guidelines.



[Phone not included]

CONTACT US



DO WE HAVE YOUR EMAIL?
DON'T MISS OUT ON
PROGRAM UPDATES.



3131 SOUTH DIXIE DRIVE, SUITE 103
MORAINE, OH 45439



937-298-8000

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, joy@swohf.org

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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