FACTOR NOTES

BROUGHT TO YOU BY THE SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

2023

ISSUE #1

CASINO NIGHT

SWOHF Casino Night will be here soon. If you attended last year, no doubt you remember the fun. Please join us on May 5th–CINCO DE MAYO–at the Dayton Woman's Club as we partake in Fiesta Festivities. There will be plenty of food, drinks, casino games, DJ, wonderful silent auction items, and more. You can scan the QR code here to register or visit the website at *swohf.org*

Please support the mission of SWOHF by supporting our fundraisers. If the Casino Night isn't your style, join us in September for the 5K for BDA. SWOHF is a non-profit that depends on generous donors to provide services, education, and support to the bleeding disorders community in Southwestern Ohio.

DO YOUR SUMMER PLANS INCLUDE

CAMP BOLD EAGLE?

For children with bleeding disorders, camp is a place where they can learn the valuable skills, they need to become independent teens and adults. They will learn from each other and from their counselors (many of whom live with bleeding disorders themselves) about ways to manage their disorder both medically and socially. At Camp Bold Eagle, kids experience a traditional summer camp environment complete with archery, arts and crafts, canoeing, swimming in a lake, and nature walks. For more information about camp opportunities and requirements, check out the Hemophilia Foundation of Michigan's website at *https://hfmich.org/camp*

Session 1: (Ages 6-9) July 9-13
Session 2: (Ages 10-12) July 15-21
Session 3: (Ages 13-17) July 23-29

Camp Bold Eagle registration is open now! SWOHF and Dayton Children's HTC partner to make going to camp a wonderful experience for your child. For directions regarding the application process, please contact us at *joy@swohf.org* **by May 19, 2023**. Once the application is submitted through the HTC as required, SWOHF will make travel arrangements for campers as well as processing scholarships provided through grant funding and generous supporters. If you have questions, contact the SWOHF office at 937-298-8000.

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HEMOPHILIA FOUNDATION
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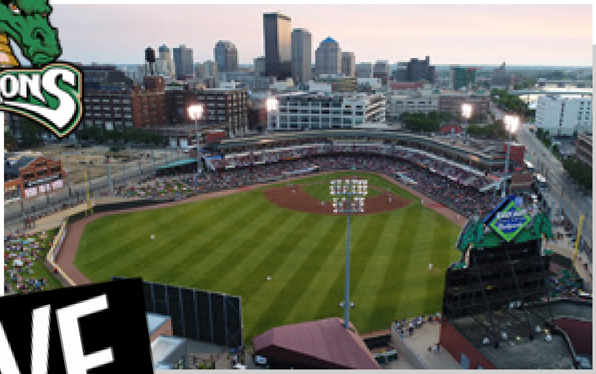
2023 EVENTS



SAVE THE DATE!

APRIL

HFA Symposium
April 13-16
Orlando, FL

MAY

Evening Out Fundraiser — Casino Night
May 5
Dayton Women's Club

Sanofi Dinner
May 11

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

Registration required for all events.

Check swohf.org or the newsletter for updates!

SEPTEMBER

Bleeding Disorders Awareness 5K
September 16
Rice Field
Miamisburg, OH

Join us!

OCTOBER

Fall Outing
October 8
Young's Dairy
Yellow Springs, OH

NOVEMBER

Women's Day
November 11
The Golden Lamb Inn
Lebanon, OH

sanofi

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WHAT IS MASAC?

Medical
And
Scientific
Advisory
Council

The Medical and Scientific Advisory Council (MASAC) is an advisory council headed by the National Hemophilia Foundation (NHF). This advisory council issues recommendations and advisories on treatment, research and other general health concerns for the inheritable blood and bleeding disorders community.

Established in 1954, MASAC is comprised of medical professionals, government agencies, and patients who possess a wide range of expertise on bleeding disorders, blood safety and infectious disease. The current chair is Amy Dunn, MD, who is an Associate Professor of Pediatrics at Nationwide Children's Hospital/Ohio State University where she is also the Director of Pediatric Hematology and directs the Hemophilia Treatment Center.

The over 400 MASAC guidelines cover a wide range of medical issues, from prevention and treatment to infectious disease complications and issues affecting women with bleeding disorders. The audience is twofold, as these guidelines are designed to provide a wealth of information for medical providers, as well as consumers.

With the consumer user in mind, MASAC designed MASAC FOR YOU (MFY) which aims to distill the important medical information found in the MASAC Guidelines, into concise, accessible language. MFY is available in both English and Spanish and are designed to be shared with medical providers, school staff, caregivers, and family members. These documents empower the community by providing straight access to reliable, expert information and can facilitate shared decision-making with health care providers.

In addition, each of the MFY publications provides links to the original MASAC Guidelines which can be utilized as comparison documents for providers who require additional detailed information and guidance. Please check out the MFY publications at:

https://www.hemophilia.org/bleeding-disorders-a-z/treatment/masac-for-you

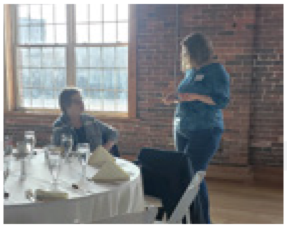
REFERENCES

Amy L. Dunn (*nationwidechildrens.org*)

https://www.hemophilia.org/bleeding-disorders-a-z/treatment/masac-for-you

https://www.hemophilia.org/who-we-are/our-team/masac

ANNUAL MEETING



Top of the Market was the venue for the 2023 Annual Meeting. A delicious breakfast was served, as we reviewed 2022 and looked to the events of 2023. Dr. Wright from the HTC updated the group with HTC happenings, and the latest news in gene therapy. Randi Clites, representing the Ohio Bleeding Disorders Council, presented her story as a mom of a son with Hemophilia A, a former Ohio legislator, and an active citizen on the council. It was a timely message as Washington Days was the following week.

Last but not least, Lindsay Carlson, Board President, presented Dena Shepard as the volunteer of the year. Dena's tireless effort on behalf of the bleeding disorders community includes service on the SWOHF board for many years now serving as our VP, Chair of the 5K for BDA walk, service on the HFA board, an advocate, fundraiser, and so much more. Thank you, Dena, for your selfless contribution!

SPONSORS FOR OUR SWOHF 2023 ANNUAL MEETING

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CSL Behring Biotherapies for Life

dayton children's

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SANOFI GENZYME

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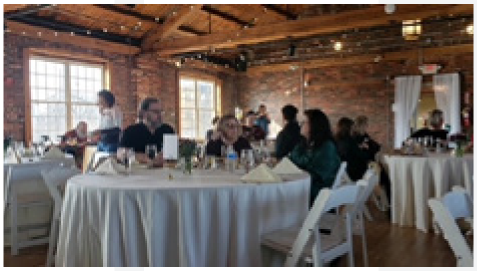
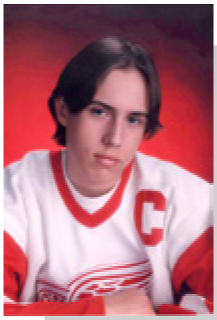


BRAD MILLER MEMORIAL SCHOLARSHIP

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.

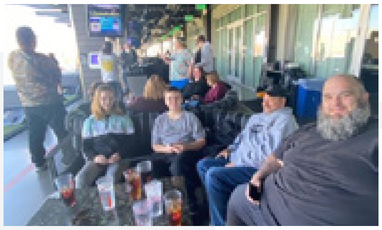
The Brad Miller Memorial Scholarship is open to any person with a bleeding disorder diagnosis, i.e., hemophilia, von Willebrand disease or other inherited bleeding disorders, who receive treatment at Dayton Children's Hemostasis and Thrombosis Center. The applicant must be seeking post-secondary education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

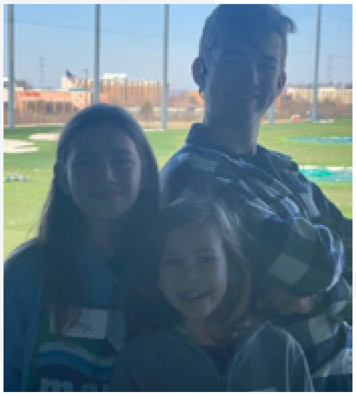
The scholarship application and supporting documents must be submitted by July 10, 2023. The decision by the scholarship committee will be announced by July 31, 2023. Payment will be made directly to the student's university/college or technical school.

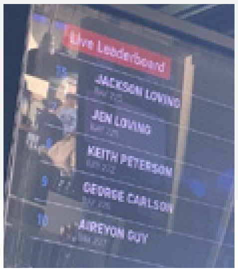
For more information about the application process, check our website for a list of requirements and to download the application form. The completed application and all supporting documentation should be submitted via email to *joy@swohf.org* by July 10, 2023.

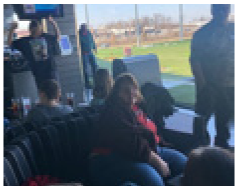
TOP GOLF

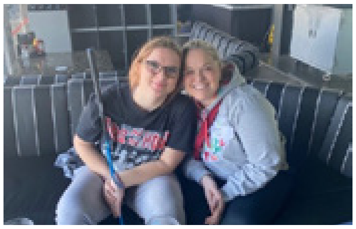
On a warm Saturday in February, CSL Behring sponsored The Common Factors educational program, featuring Pete Dyson, Patient Advocate and Getting' in the Game Athlete. Pete presented an enriching program on the benefits of physical fitness and managing a bleeding disorder. Families from SWOHF and the Tri-State Bleeding Disorders foundation enjoyed an afternoon of TOP Golf activities and lunch.











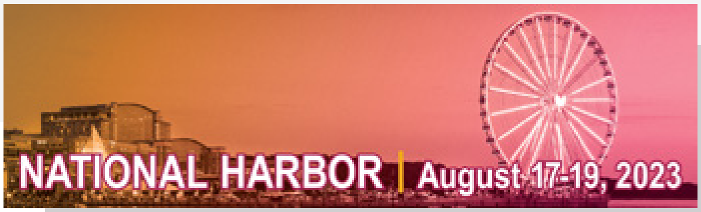
TRAVEL SCHOLARSHIPS AVAILABLE

75 Bleeding Disorders Conference #BDC2023

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.



WASHINGTON DAYS

Washington Days for the bleeding disorders was held March 8th. Constituents from across the country descended on Capitol Hill to advocate for important issues for the bleeding disorders community. The issues at stake are:

AFFORDABILITY AND ACCESS TO CARE

What are Copay Accumulator Adjustor Programs (CAAPS0 and how do they impact access?

- CAAP's say copay assistance does not count towards a patient's out of pocket (OOP0 max. Only dollars paid directly by a person count.
- People with blood disorders who need copay assistance but can't use it may have to use less or stop taking their meds. This causes complications (increased ER visits, join bleeds/damage and missed days from work/school that harm people and increase costs.
- This also affects people with other expensive conditions. NHF helps lead the All Copays Count Coalition, which includes 120 + organizations representing people with cancer, MS, HIV/AIDS and other rare and chronic conditions.
- Private plans should be required to count all copays towards a person's OOP max-regardless o who plays.

THE HELP ENSURE LOWER PATIENT (HELP) COPAYS ACT

The HELP Copays Act (HR 830) is a bipartisan bill that:

- Clarifies the Affordable Care Acts' definition for cost sharing to ensure payments made by or on behalf of patients count.
- Closes an essential health benefit (EHB) loophole, making any covered item or service part of the EHB package so that all cost sharing counts.

FEDERAL BLEEDING DISORDERS PROGRAMS

We ask Congress to support these programs:

- National Institutes of Heath (NIH): Funds biomedical research on bleeding disorders. NIH is working to implement a national blueprint for research on inhibitor prevention and eradication.
- Centers for Disease Control and Prevention (CCDC): Funds HTTC surveillance and prevention activities, and supports outreach and education programs provided by national bleeding disorders patient organizations
- Health Resources and Services Administration (HRSA): Provides funding for HTCs to provide multi-disciplinary services not typically covered by insurance, such as PT and social work services. Also as HRSA grantees, most HTC participate in the 340B drug discount program, which supports comprehensive care offered to all of their patients.

PLEASE CONSIDER JOINING WITH OHIOANS ACROSS THE STATE TO PARTICIPATE IN STATEHOUSE DAYS ON MAY 8-9.

SAVE THE DATE

FAMOHIO FAMILY EDUCATION WEEKEND

AUGUST
4 - 6, 2023

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

Save the Date!

Ohio Bleeding Disorder Council
Ohio Statehouse Day
Tuesday, May 9, 2023

Dinner and training will be provided on Monday, May 8th

Statehouse Day is open to everyone!

This year we are extending a special invitation to those who

- Depend on co-pay assistance
- Can share treatment center access
- Young adults 18-26 for the CMH increase

To RSVP please email:
obdcrsvp@gmail.com

Please visit for registration information.
www.ohiobdc.org

O B D C Ohio Bleeding Disorders Council

MEDICAID

Medicaid Unwinding…

What to do?

Due to the pandemic, Congress enacted the Families First Coronavirus Response Act (FFCRA) which required that Medicaid programs must keep recipients through the end of Covid-19. When the continuous provision ends, millions of people could lose coverage. The end date is set for March 31, 2023. Ohio began to resume routine eligibility operation on February 1. This has caused some members to be disenrolled, termination letters will be mailed in April. Given the termination of the continuous coverage provision, it is critical that Medicaid members take the following steps.

- Keep your address updated with Medicaid, contact your County Department of Job and Family Services (CDJFS) 1-844-640-6446, online *ssp.benefits.ohio.gov*
- If you have a problem…seek help. (See above)
- If you get a renewal notice, respond immediately.
- Worst response is no response.
- Get the Message Out to others that may be unaware.

Take steps to transition to other coverage if you're no longer eligible for Medicaid. Low-cost health coverage may be available through the federally facilitated marketplace at *healthcare.gov* If you need help understanding your options go to *getcoveredohio.org* or call 1-833-628-4467.

Lastly, your child may still be eligible for coverage through "Healthy Start" an Ohio Medicaid program or through the Children's Health Insurance Program (CHIP).

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.

Kroger
community rewards

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).

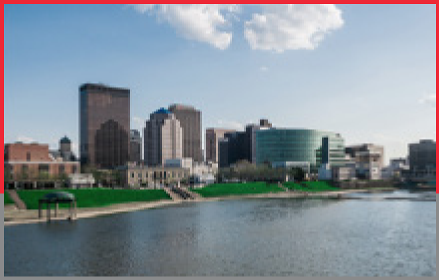
Free products are included with every order: An emergency medical ID card, a small ID charm and an exclusive engraved rectangular "InCase" phone ID that easily attaches to your cellphone case or any flat object, such as a suitcase, briefcase or laptop.

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.

American Medical ID

[Phone not included]

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.

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