FACTOR NOTES

BROUGHT TO YOU BY THE SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

2024
ISSUE #1

ARE YOU SUFFERING FROM FOMO?
(FEAR OF MISSING OUT)

You may if we don't have your email. Please contact us to get your name on the SWOHF email list.

HERE'S THE DEAL

YOU ARE INVITED TO

SWOHF CASINO NIGHT!

PROFESSIONAL GAMING TABLES
SILENT AUCTION • APPETIZERS • DRINKS

$60

PURCHASE TICKETS ONLINE AT SWOHF.ORG

FRI MAY 3

DAYTON WOMAN'S CLUB
225 NORTH LUDLOW
DAYTON OH 45402

7:00-10:30 PM

MORE INFO? CALL SWOHF OFFICE 937-298-8000 OR EMAIL DIRECTOR@SWOHF.ORG

SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION
11 West Monument, Suite 605
Dayton OH 45402

(937) 298-8000
www.swohf.org director@swohf.org

2024 EVENTS

MAY 3	Casino Night Fundraiser *Dayton Woman's Club, Ludlow Ave — Downtown Dayton*
JUL. 12-13	Family Fest Weekend *Scene 75 Dinner (Friday) and* *Dayton Dragons Game (Saturday)*
SEPT. 21	5K Bleeding Disorders Awareness Walk/Run *Rice Field, Miamisburg, OH*
OCT. 6	Fall Outing *Young's Dairy Farm, Yellow Springs, OH*
NOV. 9	Women's Day Together Educational Program & Lunch *The Golden Lamb, Lebanon, OH*

STATE AND NATIONAL ORG EVENTS

APRIL 8-9

OBDC Ohio Statehouse Days
Columbus, OH

APRIL 11-14

HFA Symposium
Indianapolis, IN
**SWOHF Travel Scholarships available*

AUGUST 9-11

FAMOHIO
Columbus, OH

SEPTEMBER 12-14

National Bleeding Disorders Foundation Conference
Atlanta, GA

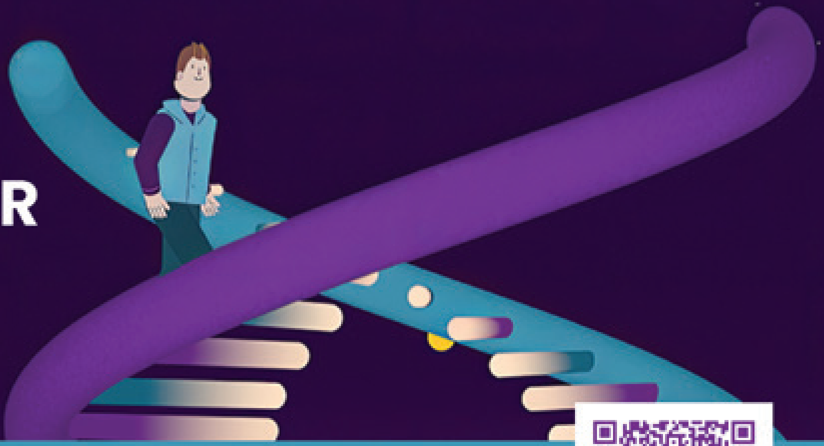
KROGER

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



LOOKING FOR THE DATE FOR

FAMOHIO'S 2024 EDUCATIONAL CONFERENCE?

AUGUST 2024

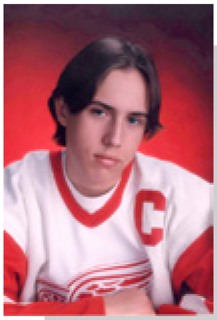
9, 10 & 11

HOPE SEE YOU THERE!

EMAIL
FAMOHIOINFO@GMAIL.COM
WWW.FAMOHIO.ORG

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, 2024. The decision by the scholarship committee will be announced by July 31, 2024. 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, 2024.

SANOFI AND BIOMATRIX EVENT

Educational event at Flemings Steakhouse sponsored by Sanofi was followed by a good time at Off Par Golf and Social sponsored by BioMatrix.

ANNUAL MEETING

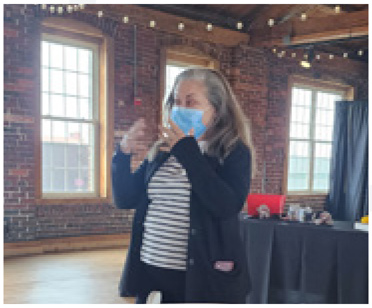
The Annual SWOHF Meeting and Volunteer breakfast was held at Top of The Market on March 2nd. We celebrated our accomplishments in 2023 as it was a novel year. We relocated to downtown Dayton; while this wasn't a planned move, it has been a smooth one. The historic 11 West Monument Building has become our new home. We've adapted well to the smaller space and are enjoying our new view overlooking the Great Miami River.

Better Together sums up the mood of 2023. SWOHF has been in the Southwestern Ohio community for over 30 years as a resource to anyone affected by bleeding disorders. The community has been through numerous changes over the years and through it all we remain steadfast in support of YOU! We've grown too! As information is abundant and treatments have become more advanced, we will pursue the most effective avenues to be a solid partner in your journey. Sometimes it will be changes to the norm or rely on cooperative partnerships with other chapters in the state. However, concentrating on YOU is always our #1 priority. Join us in 2024 and let's make this a year to remember!

The SWOHF Board laid out the plans for 2024 (see our save the date page).

Tim Wicks-HFM Camp and Youth Services Director spoke to us about the life-changing effect summer camp can have on a person with a bleeding disorder. There are so many opportunities to participate in camp. Perhaps there is one for you. (2024 Camp Details out soon)

We also highlighted our volunteers. Julie Sampson was named volunteer of the year. Julie has gone above and beyond for SWOHF for many years, helping out in many ways most notably on the Casino Night. A big Thank You to Julie for her dedication and commitment to the community.



accredo

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SANOFI GENZYME

Takeda

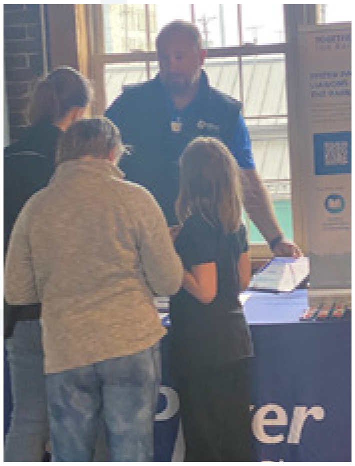
CASCADE HEMOPHILIA CONSORTIUM

dayton children's

Bayer

Genentech
A Member of the Roche Group

novo nordisk



CAMP BOLD EAGLE

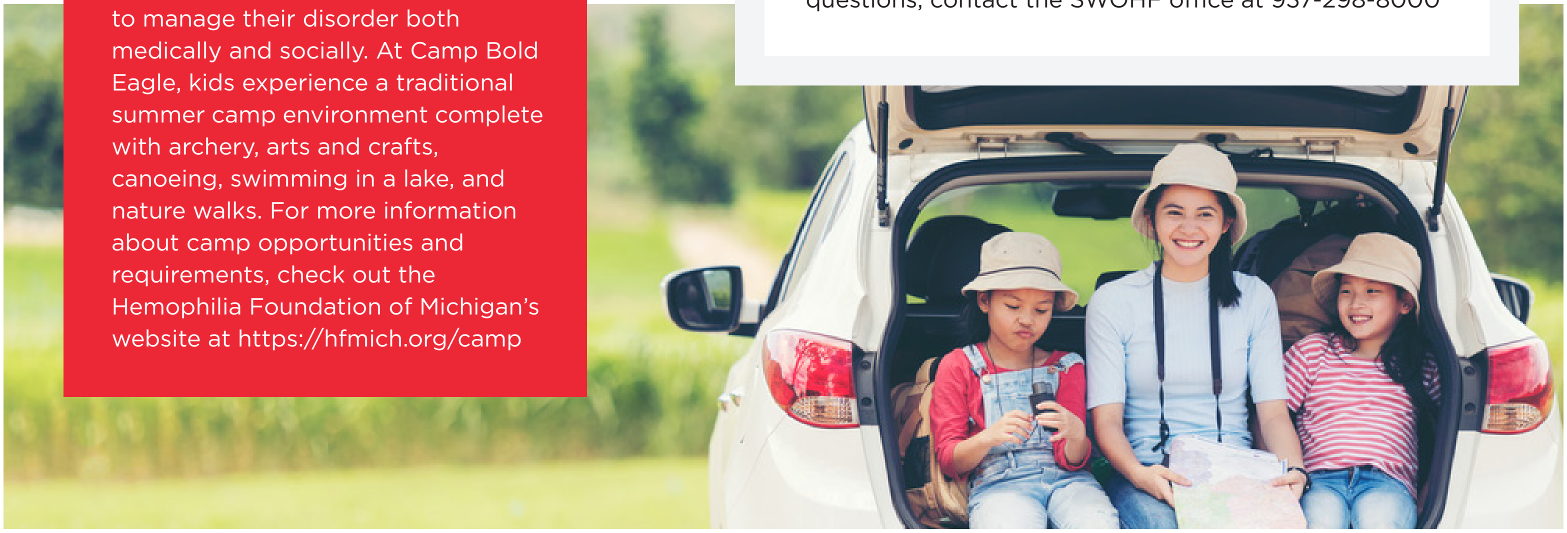
For children with bleeding disorders, camp is a place where they can learn the valuable skills, they need to become independent teens and adults. They will learn from each other and from their counselors (many of whom live with bleeding disorders themselves) about ways to manage their disorder both medically 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

TEEN CAMP: Ages 13-17 June 30 - July 6

SESSION 1: Ages 6-9 July 14-16

SESSION 2: Ages 10-12 July 20-26

Camp Bold Eagle registration is open now! 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



Washington Days

WASHINGTON, DC ♦ MARCH 6-8, 2024

NATIONAL **BLEEDING DISORDERS** FOUNDATION

A warm day in March was the setting as members of the bleeding disorders community from around the country came together on Capitol Hill. In Ohio, we met with nine representatives/aides to discuss pressing issues with lawmakers (see FAQ on Policy Asks.)

Ohio Statehouse Days

The collective and urgent voice of the community is a powerful one. We need YOU! There is still time to register for Ohio Statehouse Days on April 9th.

REGISTER NOW!!!

FAQ On Policy Asks

What are Copay Accumulator Adjustor Programs?

- CAAPs say copay assistance does not count towards a patient's OOP max or deductible. Only dollars paid directly by a person count.
- People who need copay assistance but can't use it may have to use less of or stop taking their meds. This causes complications (increased ER visits, joint bleeds/ damage, and missed days from work/school) that harm people and increase costs.
- This also affects people with other conditions. NBDF helps lead the All Copays Count Coalition, which includes 120+ orgs for people with cancer, MS, HIV/AIDS, and other rare and chronic conditions.

What is the HELP Copays Act?

- The HELP Copays Act (H.R. 830/S. 1375) is bipartisan legislation introduced by Reps. Carter (R-GA) and Barragan (D-CA) and Senators Marshall (R-KS) and Kaine (D-VA) that:
  - Clarifies the ACA's definition for cost sharing to ensure payments made "by or on behalf of" patients count.
  - Closes an EHB loophole, making any covered item or service part of the EHB package, so that all cost sharing counts.
- There are 109 bipartisan cosponsors in the House and 16 bipartisan cosponsors in the Senate.
- **ASK: Ask Representative or Senator to co-sponsor H.R. 830/S. 1375**

What does the ACA require plans to cover for prescription drugs?

- ACA EHB policies say that plans must cover (1) one prescription drug in every USP therapeutic category and class; or (2) the same number of drugs in each USP category and class as the state's EHB-benchmark plan.
- EHB regulations also require plans to cover drug treatment regiments that "treat all disease states."

How are bleeding disorders treatments classified?

- Currently, the USP combines drugs for hemophilia A, hemophilia B, hemophilia with inhibitors, von Willebrand Disease and deficiencies of Factor VII, X, and XIII into a single category (Blood Products and Modifiers) and single class (Blood Component Deficiency/Replacement).
- This allows insurers and health plans to comply with EHB rules while still severely limiting access to critical medication.

What are we seeing?

- Health plans are putting as few as one or two bleeding disorder products on formulary, restricting access to needed medications and sometimes not including a treatment for every disorder (i.e., they cover a drug for hemophilia A but not hemophilia B).
- We need HHS to enforce all EHB regulations ASAP so more plans don't institute really narrow formularies.

FAQ About CAAPS

- Has there been activity on the state level?
  - Yes, 19 states, Puerto Rico and Washington, DC have enacted laws, but we need Congress to act so that all types of private plans are included.
- Wasn't there a lawsuit on this issue?
  - Yes, there has been lots of back and forth but a judge recently ruled in favor of patients and affirmed that insurers *cannot* implement CAAPs for brand name drugs that don't have generic equivalents. But we are still waiting on rulemaking from HHS for clarity and this policy is not being enforced today.
  - We want the HELP Copays Act to become law so that there is clarity that no CAAPs are allowed!
- Does the bill have a score?
  - The CBO has not issued an official score (what the legislation would cost the government) but we do expect there will be a cost for the bill.

What can Congress do?

- We are asking Congress to ask HHS to enforce current EHB regulations that require plans to cover drugs that treat all disease states. This would mean that plans must cover more bleeding disorders treatments, despite them being in just 1 category and class.
- **ASK: Ask Representatives to sign letter to HHS. Ask Senators if they would lead a similar letter.**

What's with all the letters?
ACA = Affordable Care Act
CAAPs = Copay Accumulator Adjustor Programs
CBO = Congressional Budget Office
EHB = Essential Health Benefits
HHS = US Department of Health & Human Services
OOP = out-of-pocket maximum
USP = United States Pharmacopeia

WORLD **HEMOPHILIA** DAY 2024

By Melissa Tucker

April 17, 2024 is the day the bleeding disorders communities across the globe will celebrate World Hemophilia Day and we at the HTC are loving this year's theme: "Equitable access for all: recognizing all bleeding disorders". According to the Centers for Disease Control and Prevention (Office of Health Equity 7/1/2022), Health Equity is the state in which everyone has a fair and just opportunity to attain their highest level of health. The Dayton Children's Center for Health Equity is committed to optimal health for all children and has a team of over 25 diverse, dedicated, talented, and creative team members working to carry out the vision of reinventing the path to children's health. The goal of the Center for Health Equity is to better understand the health disparities that exist amongst our children, identify the reasons behind why a child is not thriving and work with the community to provide the support necessary. In the upcoming months you will begin to receive a short Social Needs Screening form when attending appointments at Dayton Children's. The screenings ask questions such as if you have had a hard time gaining access to transportation, food, shelter, and medical care over the previous 12 months. One way in which we can address and improve health outcomes and equitable care for those we serve is by addressing their social needs. These screenings will help us identify unmet social needs that our patients may be experiencing and help us to intervene with resources and assistance. Dayton Children's aims to empower all families to get the assistance they may need, please take the time to complete the screenings knowing they are confidential. If you are in need of help or assistance please remember that your HTC team is here for you and can be reached at 937-641-3111.

> ***"Equitable access for all: recognizing all bleeding disorders".***

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.

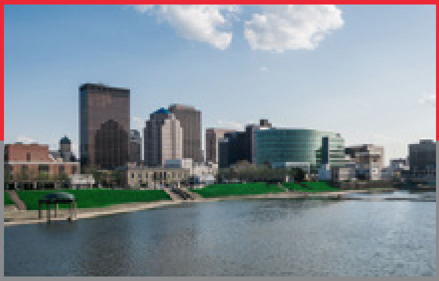
SWOHF is grateful for grant funding and donations that facilitate these purchases on behalf of our Greater Dayton Bleeding Disorders Community. So when you go to the HTC for your next visit, you can view sample products available and complete a form to request a new bracelet or necklace according to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

American Medical ID

[Phone not included]

CONTACT US

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



**11 WEST MONUMENT, SUITE 605
DAYTON, OH 45402**

937-298-8000

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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
11 West Monument, Suite 605
Dayton, OH 45402

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