

SWOHF

A newsletter for the friends and family of
the Southwestern Ohio
Hemophilia Foundation



NOTES

2026 ISSUE # 1



MARCH

Bleeding Disorders

AWARENESS MONTH

CASINO NIGHT

NIGHT

PROFESSIONAL GAMING TABLES

EVENT RESCHEDULED

**JUNE 26
FRIDAY**

7:00 PM TO 10:30 PM
DAYTON WOMAN'S CLUB
\$60 PER PERSON

Scan QR code to
buy tickets NOW!

SILENT AUCTION
APPETIZERS





2026 SWOHF EVENTS



June 12-13 Family Fest Weekend

Scene 75 Dinner (Fri) & Dayton Dragons Game (Sat)



June 26 CASINO NIGHT FUNDRAISER

EVENT RESCHEDULED

Dayton Woman's Club, Ludlow Ave—Downtown Dayton



September 19 Bleeding Disorders Awareness 5K Walk/Run

Rice Field, Miamisburg OH



October 4 Fall Outing

Young's Dairy Farm, Yellow Springs, OH



November 14 Women's Day Together

Educational Program & Lunch

The Golden Lamb, Lebanon, OH



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.



**COULDN'T BE EASIER.
SUPPORT SWOHF!**



CAMP REGISTRATION NOW OPEN

CAMP BOLD EAGLE

Session 1: (Ages 6-9) July 12-16, 2026

Session 2: (Ages 10-12) July 18-24, 2026

Teen Camp: (Ages 13-17) June 28-July 4, 2026

EAGLE OUTPOST Ages 14-15 August 2-8, 2026

Camp Bold Eagle registration is open now! Once the application is submitted through the HTC is 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



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>

VOLUNTEER OF THE YEAR

Lindsay Carlson



Lindsay has led the SWOHF chapter as the Board President for over six years. She has been a dedicated ally to us as we have navigated COVID-19, staff and program changes.

Her lived experience as mother of three boys with Hemophilia A, as well as teaching English at the high school level, has given her some unique insights. We are grateful for her leadership and thrilled that she has elected to remain on the SWOHF Board as an advocate, supporter and friend.

Thank you, Lindsay!

ANNOUNCING CHANGES TO THE SWOHF BOARD LEADERSHIP

Welcome Billy Cline to his newly elected role as SWOHF Board President!

Billy has served on the SWOHF Board for a year. His passion for the bleeding disorders community, especially in advocacy for healthcare access has made him an invaluable part of the board. We look forward to his leadership.

Currently, he works as a Project Manager on the I.T. side of healthcare on the state level. Prior to that he participated in advocacy with Baxter Pharmaceuticals. He was a part of their True Identity Program where he would share his story, growing up with Hemophilia.

He looks forward to learning from all the various people living with Bleeding Disorders and collaborating with all the wonderful resources to work to make a difference for the better in patients' lives. We are certain that his unique perspective will be impactful in this inspirational role.





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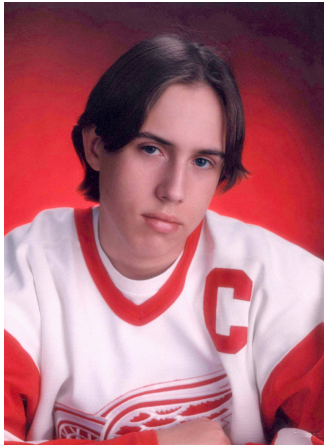


**Connect with your Pfizer Patient Navigator
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*Pfizer Patient Navigators are not measured or awarded based on sales performance nor will they ask you to switch products.

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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** 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 1, 2026. The decision by the scholarship committee will be announced by July 31, 2026. 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 1, 2026.



SCHOLARSHIP TIPS

- 1 PAY ATTENTION to details and requirements.
- 2 STAY ORGANIZED
- 3 STAND OUT: Share your accomplishments.
- 4 BE PERSONAL: What drives you?
- 5 RESEARCH. Research. Research. There are thousands of scholarships out there and many don't get applicants.
- 6 PROOFREAD your application. Check for spelling and punctuation.

BE MINDFUL OF DEADLINES.

Download application for Brad Miller Memorial Scholarship. Scan QR code for more info at swohf.org



ADVOCACY



Advocacy Outlook NBDF Washington Days 2026 Talking Points

Once again patients and families from across the country arrived in Washington DC the first week of March. The mandate to make the case for affordable health care and access was priority # 1. Lawmakers met with constituents to hear out the concerns of the community. The Southwestern Ohio group consisted of patients and healthcare advocates. To further the discussion of the important issues concerning us all, the following questions were directed for their consideration.



Ohio Bleeding Disorders Council



Ask #1: Support federal bleeding disorders programs

We explained that federal bleeding disorders programs at HRSA and CDC provide critical funding to HTC's and help support research, care, and public health monitoring for bleeding disorders. Each program receives modest funding that yields big returns in helping people with bleeding disorders and lowering health care spending. We asked lawmakers to continue their support of these programs and let us know if they are interested in leading a letter in the Senate.

Ask #2: Co-sponsor the Help Ensure Lower Patient (HELP) Copays Act

About 55% of the bleeding disorders community has private coverage through work or the Marketplace. Due to the high, life-long costs of bleeding disorders care, out-of-pocket (OOP) expenses are extremely high even for those with good insurance. Many people use copay assistance programs to afford their cost-sharing and stay on treatment. But that lifeline is fraying due to health insurer/PBM practices that disallow copay assistance from counting toward patient cost sharing. The HELP Copay Act is bipartisan legislation that bans these abusive practices and ensures that patients can access their medication. We ask members of congress to co-sponsor H>R> 6423/S. 864 to "make all copays count."

Ask #3: Be an original co-sponsor on legislation addressing needs of women and girls with bleeding disorders

Due to longstanding misconceptions that only males have bleeding disorders, women and girls have been blocked from accessing timely diagnoses, medically appropriate care, and have been excluded from research. Without diagnosis, women will not receive proper care/treatment from a provider with the requisite expertise, such as a hemophilia treatment center. The Fostering Effective Diagnosis and Treatment for Underserved Populations (FED UP) with Bleeding Disorders Act calls for an inter-agency review to evaluate the status of and identify new opportunities for research, access to treatment, and education and training of providers, with the aim of advancing care for women and girls with bleeding disorders.

Rep. Julie Johnson (D-TX) has committed to leading the FED UP with Bleeding Disorders Act. NBDF is seeking a republican co-lead prior to introducing the legislation. We ask house members to join Rep. Johnson(D-TX) in supporting policies that will work to remove barriers for women and girls living with bleeding disorders. We ask Senate members to consider leading companion legislation in the Senate.

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SWOHF Annual Meeting and Volunteer appreciation lunch at the Boonshoft Museum of Discovery

Every year we hold a public acknowledgement of our past year' highlights and identify the plans for the new year. Once again, we were joined by our patient families, Industry Partners, and healthcare professionals from Dayton Children's Hemophilia Treatment Center.

We were fortunate to hear from Dr. Jordan Wright as he addressed various inquiries in an Ask the Doc Q & A. Thanks to those who submitted very thoughtful questions. The day was capped off by a lovely catered lunch from Submarine House and time spent enjoying the Boonshoft Museum.



March 07, 2025



Special Thanks to our 2025 volunteers including our SWOHF Board, Lisa Geers, Ava Linder, Barry Linder, Kaitlyn Mahaffey, Lauren Sears, Courtney Marker, Denise Crowley, Teresa Howard, Larry Justice, Suzi Justice, Angie Morgan, Gregg Vanover, Berry Wyatt, Amber Shawen
We couldn't do it without You!!

Thank You
 VOLUNTEERS



2025 SWOHF Board

- Lindsay Carlson, President
- Dena Shepard, Vice President
- Carolyn Brown, Treasurer
- Deb Kremer-Smith, Secretary
- Dick Miller
- Katie Perkins
- Cheryl Coffey
- Billy Cline





ANNUAL MEETING 2026

THANK YOU



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HEMOPHILIA ALLIANCE



BLEEDING DISORDERS CONFERENCE

Orlando, Florida • August 13-15, 2026

We hope you join us in Orlando, Florida for a premiere three-day event designed to connect, educate, and empower those in the Bleeding Disorders community. NBDF offers a program full of rich educational sessions, engaging networking opportunities, and a vibrant exhibit hall showcasing the latest advancements in research and patient care. Aurora's stunning scenery and family-friendly venue will make this an unforgettable experience for both professional development and relaxation. All sessions, industry symposia, social events, and the Exhibit Hall will be conveniently located in the hotel's Convention Center.

NBDF is pleased to offer a discounted room rate and daily resort fee at the **Orlando World Center Marriott** for conference attendees. Availability is limited, so register now to secure your room at this stunning resort! For more info, check NBDF website <https://www.bleeding.org/events/bleeding-disorders-conference>

SWOHF TRAVEL SCHOLARSHIPS AVAILABLE

SWOHF is pleased to offer scholarship opportunities for travel to our national organization conferences. These scholarships are awarded by the SWOHF Board after review of all applications received. The scholarships are open to individuals in our community diagnosed with a bleeding disorder who live in the Greater Dayton area and are treated at Dayton Children's HTC or Dayton area hematologist. The scholarship is for one individual affected by a bleeding disorder and one immediate family member only.

This scholarship award is intended to solely cover: Registration to the HFA Symposium or NBDF Annual Bleeding Disorders Conference; Airline Reservations; Hotel Accommodations. If granted this scholarship, the award is solely for direct expenses: travel expenses and hotel will be paid directly by SWOHF. Before you apply, please be aware that there will be other costs to attend; for example: meals, taxi/shuttle, baggage, and other miscellaneous expenses. SWOHF is not responsible for any additional expenses of the trip.

**SCAN QR CODE TO
DOWNLOAD TRAVEL
SCHOLARSHIP
APPLICATION FROM
SWOHF.ORG WEBSITE**



ORLANDO

WHAT'S NEXT? YOU DECIDE.

At Genentech, we're committed to supporting the hemophilia A community in ways that go beyond treatment and focus on you as a person. From sharing real stories and experiences from our Patient Ambassadors, to an educational rap anthem for a hemophilia A treatment, to one-on-one support from a team of experts, we're here to help you take on what comes next.



SCAN THE QR CODE TO SEE HOW
GENENTECH AND THE HEMOPHILIA
A COMMUNITY ARE EMBRACING
WHAT'S NEXT, TOGETHER.



HOW THE ONE BIG BEAUTIFUL BILL ACT (OBBBA) MIGHT AFFECT PATIENTS



KEY CHANGES TO MEDICAID UNDER OBBBA

By 2027

- **Community engagement/work requirements** of 80 hours per month¹
- More frequent **eligibility verification**—every 6 months instead of yearly¹
- **Reduced retroactive coverage** from 3 months to 1 month¹

By 2028

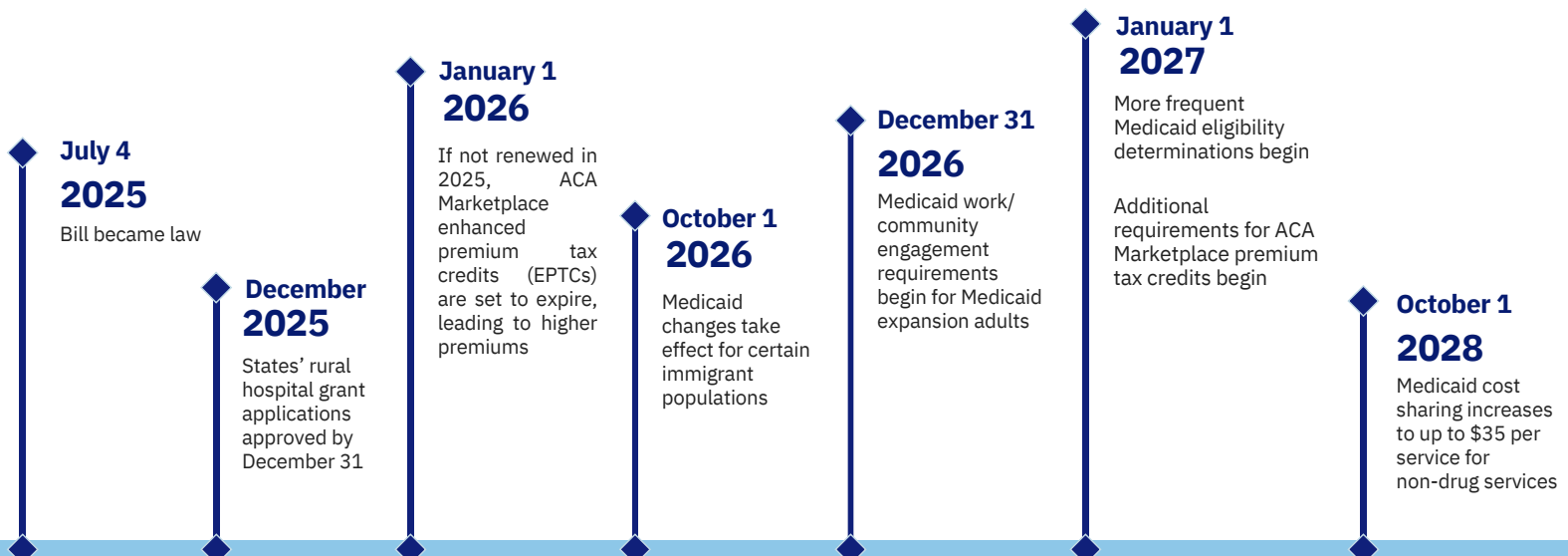
- **Some patients may need to pay up to \$35 out of pocket** for each medical service (does not apply to prescription drugs)¹



WHY IS THIS IMPORTANT?

- New reporting and enrollment requirements are projected to **increase the number of uninsured patients**²
- All Medicaid enrollees should be prepared/ready to **keep their contact information up to date** to prevent becoming uninsured
- Patients face **greater risk of losing Medicaid coverage** even if they remain eligible due to stricter eligibility and new administrative requirements¹
- There may be **additional utilization management protocols** for high cost services¹

DATES WHEN KEY PROVISIONS GO INTO EFFECT³



HOW THE ONE BIG BEAUTIFUL BILL ACT (OBBBA) MIGHT AFFECT PATIENTS (CONT)

WHAT CAN YOU DO TO HELP YOUR PATIENTS THROUGH THIS PROCESS?

1. Remind patients that, in most states, **open enrollment starts November 1, 2025, and runs through January 15, 2026**. To ensure continuous coverage starting January 1, 2026, a patient will need to renew their coverage by December 15, 2025. Congress is currently debating whether to extend the enhanced premium tax credits that have made health insurance more affordable for millions of Americans, and if these credits are not renewed by the end of the year, the amount of financial assistance to purchase a plan may change.⁵
2. Remember that essential **preventive services, including some** primary care, mental health, and substance use disorder **services**, are generally exempt from the new co-payments. Do not let co-pay concerns prevent patients from seeking these critical services.⁶
3. Remind patients to **look for and respond to mail, email, or phone calls** from their state Medicaid office to understand their coverage and renewal requirements.
Note: Some Medicaid plans might go by different names in some states. Make sure patients are aware of their plan name if applicable.

4. Encourage patients to proactively **update their contact information with the state** and to complete their renewal application promptly.



**Medicaid.gov
Renewal
Resources**

5. If patients no longer qualify for Medicaid, help educate them about their insurance options— Genentech has **videos and other resources to help**.



**Genentech
Understanding
Health Insurance
Resources**

 You can learn more about what's happening in your state by visiting [Medicaid.gov](https://www.Medicaid.gov).

References: **1.** Kaiser Family Foundation. Health provisions in the 2025 federal budget reconciliation law. Published August 4, 2025. Updated August 22, 2025. Accessed October 27, 2025. <https://www.kff.org/report-section/health-provisions-in-the-2025-federal-budget-reconciliation-law-medicaid/> **2.** Kaiser Family Foundation. Allocating CBO's estimates of federal Medicaid spending reductions across the states: enacted reconciliation package. Published July 1, 2025. Updated July 23, 2025. Accessed October 27, 2025. <https://www.kff.org/medicaid/allocating-cbos-estimates-of-federal-medicaid-spending-reductions-across-the-states-enacted-reconciliation-package/> **3.** Kaiser Family Foundation. Implementation dates for 2025 budget reconciliation law. Accessed October 27, 2025. <https://www.kff.org/implementation-dates-for-2025-budget-reconciliation-law/> **4.** A quick guide to the Health Insurance Marketplace.® Accessed October 27, 2025. <https://www.healthcare.gov/quick-guide/dates-and-deadlines/> **5.** Enhanced premium tax credit expiration: frequently asked questions. Accessed October 27, 2025. [https://www.congress.gov/crs-product/R48290#:~:text=September%2024%2C%202025%20\(R48290%20%2D,September%2024%2C%202025%20\(R48290](https://www.congress.gov/crs-product/R48290#:~:text=September%2024%2C%202025%20(R48290%20%2D,September%2024%2C%202025%20(R48290) **6.** Health benefits & coverage. HealthCare.gov. Accessed October 27, 2025. <https://www.healthcare.gov/coverage/preventive-care-benefits/>



OHIO DENTAL PLAN COVERAGE Who is eligible? The Ohio Dental Program is open to bleeding disorder patients with VWD or Hemophilia in Ohio who have NO AVAILABLE dental coverage through any other source. Dependents may also be eligible, based on need and availability. Where does the plan coverage come from? The Greater Ohio Bleeding Disorders Foundation acts as the fiscal agent for all Ohio chapters and HTC's for the Ohio Dental Program. GOBDF coordinates coverage with Delta Dental. What does it cost? There is an annual \$25 per person enrollment fee for a person with a bleeding disorder and \$50 each for additional family members with a \$200 per family maximum. Each enrollee will also have a \$100 deductible due to the dentist for services over and above exams/cleanings. Each family has an annual maximum of \$300 out of pocket. The monthly premium costs will be paid out of grants that were written and supported by all Ohio chapters and HTC's from Cascade Hemophilia Consortium and other HTC's funds. There may be assistance available for bleeding disorder patients to meet out of pocket costs. Contact Program Manager for more details. What is the coverage? Up to FOUR free cleanings per year, per enrollee. Also, includes \$1,250 in services per enrollee.

What is the coverage? Up to FOUR free cleanings per year, per enrollee. Also, includes \$1,250 in services per enrollee.

Services Amount of Coverage:

- Class I Services 4 Exams/cleanings per year, x-rays – paid at 100% Deductible Applies to basic and major services only – \$100 per individual. \$300 Family maximum.
- Class II Services Fillings, extractions, crowns, relines & repairs – paid at 100% after deductible
- Class III Services Bridges, implants, dentures – paid at 100% after deductible Annual Maximum \$1,250 Individual annual limit applies to all services except diagnostic & preventative



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PLAN APPLICATION
FROM SWOHF.ORG
WEBSITE**

Who accepts the Delta Dental Plan? Most dentists accept Delta Dental. A list of dentists who participate in Delta Dental's Preferred and Premier networks can be found at www.deltadental.com. Click on "Find a Dentist" on the right side of the screen, or call your current dentist to ask if they accept Delta Dental PPN. When can I sign up for coverage? The applications are available year-round and placement into the program is done throughout the year based on availability. Send in your application asap. New enrollees will be added at the beginning of each month. You will get a call when your application is received. Contact your HTC or Chapter for more information or call the program manager, Randi Clites at 330-730-1259. How long will I be covered? To maintain coverage on the Dental Program, you must meet comprehensive care guidelines. Patients must attend comprehensive clinic based on recommendations of their provider. You will be required to receive at least one dental cleaning a year to qualify to reapply during annual enrollment periods. As long as you stay compliant, you will maintain coverage as long as it is needed.



In collaboration with Dayton Children's HTC, SWOHF continues its 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 reasonable.

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.

SWOHF MISSION

Southwestern Ohio Hemophilia Foundation (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.



SUPPORT EDUCATE ADVOCATE



DISCLAIMER The material provided in SWOHF 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.

Check our website swohf.org

Email: director@swohf.org

Phone: 937-298-8000

Executive Director: Joy Linder

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