SWOHF NOTES

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

2025 ISSUE #2

SWOHF 15TH ANNUAL

BLEEDING DISORDER AWARENESS

RUN/WALK 5K

IN SUPPORT OF SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

SEPT 20

SATURDAY

RICE FIELD MIAMISBURG

5K BEGINS AT 10:00 A.M.

SCAN ME!

REGISTER ONLINE
www.ItsYourRace.com
$25 PER PERSON

T-SHIRTS!!

AWARDS!!

2025 SWOHF EVENTS

July 25-26	**Family Fest Weekend**
	***Scene 75 Dinner** (Friday) **& Dayton Dragons Game** (Saturday)*
September 20	**5K Bleeding Disorders Awareness Walk/Run**
	Rice Field, Miamisburg OH
October 5	**Fall Outing**
	Young's Dairy Farm, Yellow Springs, OH
November 8	**Women's Day Together Educational Program & Lunch**
	The Golden Lamb, Lebanon, OH

More info? Check website FAHOHIO.org
Questions? FAHOHIOinfo@gmail.com

COULDN'T BE EASIER. SUPPORT SWOHF

for

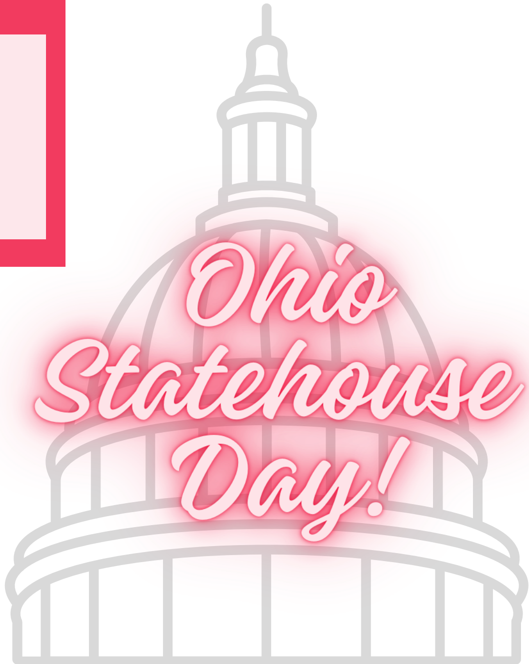
SWOHF
SOUTHWESTERN OHIO
HEMOPHILIA FOUNDATION

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.

ADVOCACY

Advocacy is in our blood

Ohio Bleeding Disorders Council



Ohio Statehouse Day!

About 50 bleeding disorders advocates stormed the Ohio Statehouse in Columbus wearing red to raise awareness for bleeding disorders on Wednesday, March 19th. Our advocates attended meetings with 12 Senators, 14 State Representatives, and four Administrative Staff members throughout the day. OBDC advocates shared their stories on how copay assistance is an essential financial resource to access bleeding disorders treatment and asked for support in the state budget for the (B)CMH Treatment Program age to be increased up to 26 years old. OBDC also hosted a luncheon at the Ohio Chamber, which engaged another 15 lawmakers with our advocates. To end our Advocacy Day, our advocates were recognized on the House Floor during the opening messages of the Session.

A post Statehouse Day update: on Tuesday, April 1st OBDC learned our efforts were successful and the substitute State Budget Bill included the expansion up to age 26. If you are impacted by a copay accumulator or maximizer program, your family experience is still needed to share with lawmakers to ban this practice in Ohio and at the Federal level, contact Randi Clites at randi@gobdf.org to engage in continued advocacy efforts.

AUGUST 1-3, 2025

FAM 2025

FAMILY EDUCATION WEEKEND

MARRIOTT NW - 5605 BLAZER PARKWAY - DUBLIN OH

-COLUMBUS-

REGISTER NOW

bike
safety

Bike Helmets for Kids: Parent FAQs

Article Source: "HealthyChildren.org, a resource of the American Academy of Pediatrics"

Is your child starting to discover the joy of riding a bike? To help make sure a head injury doesn't spoil their fun, don't forget a helmet! Here are some questions you may have when choosing a bicycle helmet for your child.

How should a child's bicycle helmet fit?
A helmet should be worn squarely on top of the head, covering the top of the forehead. Your child should be able to see the brim of the helmet when glancing up. Make sure the helmet sits parallel to the ground when your child's head is upright. If it is tipped back, it will not protect their forehead. The helmet fits well if it doesn't move around on the head or slide down over your child's eyes when it is pushed or pulled, or your child shakes their head. The chin strap should be adjusted to fit snugly.

How can I tell if a bike helmet will keep my child safe?
You should only buy a helmet that meets the bicycle helmet safety standards of the U.S. Consumer Product Safety Commission (CPSC). Any helmet meeting these standards is labeled. Check the inside of the helmet to confirm.

Do all bicycle helmets for kids meet these safety standards?
All helmets manufactured or imported for use after March 1999 must comply with a mandatory safety standard issued by the CPSC.

Can other kinds of helmets be used for bicycling?
Each type of helmet is designed for protection in specific conditions and may not offer enough protection in bike crashes or falls. Bike helmets are very protective in head-first falls at fairly high speeds. Helmets designed for bicycle riders are also light and well ventilated for comfort, making them less likely to be taken off. A multisport helmet, certified to meet the CPSC standard for bicycle helmets, can also be used for bicycling as well as other activities however, bicycle helmets should be used only for bicycling and not other activities.

Where can I get a bicycle helmet for my child?
Helmets meeting CPSC safety standards are available at bicycle shops and at some discount, department, and toy stores in adult, children, and toddler's sizes and styles. If you buy a helmet online, buy from a familiar retailer based in the United States, and check the label to be sure it meets the CPSC standard. Do not resell, donate, or buy a used bike helmet because it may be too old to provide protection or may have been in a crash.

Which is better: hard-shell or soft-shell helmets?
The essential part of the helmet for impact protection is a thick layer of firm polystyrene, or plastic foam, that crushes on impact, absorbing the force of the blow. All helmets require a chin strap to keep them in place in a crash.

How are hard-shell and soft-shell bike helmets different?

- Hard-shell bicycle helmets also have a hard outer shell of plastic or fiberglass that provides a shield against penetration by sharp objects. The hard shell also holds the polystyrene together if it cracks in a fall or crash. These helmets are more sturdy, but tend to be heavier and warmer than the soft-shell models.
- Soft-shell bicycle helmets have no hard outer shell but are made of an extra-thick layer of polystyrene covered with a cloth cover or surface coating. The cloth cover is an essential part of many soft-shell helmets. If the helmet comes with a cover, the cover must always be worn to hold the helmet together if the polystyrene cracks on impact.

Both types of helmets meet CPSC standards; the main difference is style and comfort. The soft-shell helmets are lighter than the hard-shell versions but may be less durable. Although there is no consensus on the relative safety of the 2 types, models of both types have passed the CPSC test. The soft-shell helmets are lighter than the hard-shell versions but may be less durable.

Are there bike helmets for infants?
Yes. Many infant-sized helmets are of the soft-shell variety. They are light, an important consideration for small children whose necks may not be strong enough to comfortably hold a hard-shell helmet. Babies younger than 1 year old have relatively weak neck structure. Neither helmets nor bike traveling is recommended for them.

How long will a child's bicycle helmet fit?
An infant's or child's helmet should fit for several years. Most models have removable fitting pads that can be replaced with thinner ones as the child's head grows. But keep in mind that helmets should be replaced every 5 years, or in the manufacturer’s recommended time frame, since materials can degrade over time.

Can a bike helmet be reused after a crash?
In general, a helmet that has been through a serious fall or crash should be retired with gratitude. It has served its purpose and may not provide adequate protection in another crash. If you are uncertain whether the helmet is still usable, throw it away.

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For information on Pfizer's hemophilia products, programs, or services, Patient Navigators (PNs)* are available to help you access the information you need.

Visit TogetherForRare.com to learn more.

*Pfizer PNs are not measured or awarded based on sales performance, nor will they ask you to switch products.

PP-HYM-USA-0222 February 2025

Pfizer

A Heartfelt Thank You to the Kremer Family & Friends for Honoring Carolyn Catherine Kremer Through Donations to SWOHF

Carolyn Catherine Kremer, age 86, died on March 15, 2025. In her honor, her family chose to have memorial contributions made to SWOHF. Carolyn's daughter, Debra Kremer-Smith, is a long-time Board member of SWOHF, currently serving in the role of Secretary.

Carolyn is survived by four children, Debra & Scott Smith, Yorkshire, Tami & Jim Kueterman, Tipp City, Dan & Nancy (Evers) Kremer, Yorkshire, and Kevin Kremer, Tipp City; 16 grandchildren, 10 great grandchildren, a brother, Dale Dues of Cabot, AR, and a sister-in-law, Betty Tumbusch.

We want to express our deepest gratitude to all who gave so generously in her memory. By celebrating the life of someone they loved dearly, they also extended her spirit of compassion to others in need. Carolyn was someone who believed in lifting others up, and it brings comfort to know that her legacy continues through the good that these gifts will do.

Whether your donation was big or small, know that it made a difference and that impact will be felt far beyond this moment. Thank you for honoring Carolyn's life in a way that reflects the values she held dear. Your kindness is a testament to the strength of the Kremer family and the love they continue to share.

SWOHF occasionally hosts **exclusive dinners** at local **restaurants** on behalf of **pharmaceutical companies**. These events are designed to provide in-depth, diagnosis-specific education and offer valuable opportunities to explore the latest advancements in medicine and **innovative technologies.**

If you're looking to stay at the forefront of **medical knowledge** and connect with professionals in the field, attending one of these dinners could be a great opportunity. It's an excellent chance to **gain insights** into cutting-edge treatments, engage in meaningful discussions, and **network** with partners and friends.

We often use email to send these invitations. Please send an email to director@swohf.org if you are not currently receiving our email invitations.

Casino Night

thanks

FOR YOUR SUPPORT

CSL Behring

CASCADE HEMOPHILIA CONSORTIUM

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THANK YOU

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THE PICKLE LODGE
THE PUB
THE SPICY OLIVE
TOP GOLF
WILD AXE THROWING
YOUNG'S DAIRY

CAROLYN BROWN
LINDSAY CARLSON
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For Subcutaneous Use Only
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Rx only
Before first use: Store refrigerated
0
mg

Judy Doyle

Patient advocate

About Judy

Judy is a Novo Nordisk Hemophilia Community Liaison with 18 years of experience supporting those with bleeding disorders. She loves the passion of the hemophilia community to get things done and not let things stand in their way.

Hemophilia Community Liaison

OH, IN

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NATIONAL
BLEEDING DISORDERS
FOUNDATION

SWOHF's Continued Commitment to Research

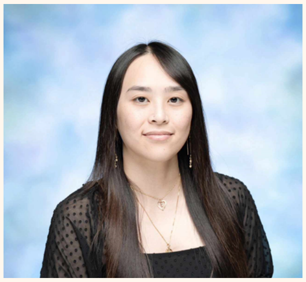
NBDF is grateful for all of the chapters and individuals that make JGP possible, investing in research that deepens our understanding of inheritable bleeding disorders and fuels new treatment options. RESEARCH is important to the entire bleeding disorders community. Chapters that donate realize they are investing in a brighter future.

Judith Graham Pool Postdoctoral Research Fellowship Awardees Announced

Dr. Judith Graham Pool revolutionized the treatment of hemophilia. Born in 1919, Dr. Pool's work on isolating Factor VIII led to the creation of cryoprecipitate, changing lives for those with bleeding disorders. Her legacy extends beyond her scientific achievements, advocating for women in science and leading change. A true hero in the field of blood science!

NBDF's premier research fellowship program is named in honor of Dr. Judith Graham Pool. Established by NBDF in 1972, the Judith Graham Pool (JGP) Postdoctoral Research Fellowships have provided a long legacy of support for basic science and pre-clinical research in bleeding disorders. Since the program's inception, NBDF has funded numerous scientists whose projects have produced vital insights into hemophilia and other bleeding disorders. JGP research fellowship award projects have contributed to the development of safer concentrates, enhanced methods of testing and screening, and have laid the groundwork for current advances in gene therapy for hemophilia.

Award: Judith Graham Pool Postdoctoral Research Fellowship
Awardee: Dr. Huong Chau // Institution: Stanford University



Bio: Dr. Chau obtained her Bachelor of Science in Biomolecular Engineering from Santa Clara University in 2019 and her Ph.D. in Integrative Pathobiology from the University of California, Davis in 2024. Currently, she is a postdoctoral researcher at the Stanford School of Medicine, working under the mentorship of Dr. Glaivy Batsuli. Her research focuses on elucidating the innate immune response to factor IX (FIX) utilizing her expertise in bioinformatics to bridge gaps in the understanding of immune tolerance and reduce antigenicity in hemophilia B treatments.

Lay summary of funded research project: People with hemophilia B are at risk of bleeding, sometimes even without injury. Early diagnosis and starting factor IX (FIX) therapy are crucial, especially for severe cases. However, around 3-10% of people with hemophilia B develop inhibitors that block FIX treatment, making bleeding harder to control. Unlike hemophilia A, treatment options for hemophilia B with inhibitors are limited due to possible severe reactions. Our research aims to understand how the immune system responds to FIX and why these inhibitors form by studying specific immune cells and a protein called IL-13. These findings could help improve treatments for FIX inhibitors.

Award: Judith Graham Pool Postdoctoral Research Fellowship
Awardee: Dr. Marisa Brake // Institution: Beth Israel Deaconess Medical Center

Bio: Dr. Brake has a background in genetics, molecular biology, and biochemistry, with research experience spanning thrombosis genetics, publications in PNAS and JCI, and multiple academic awards. Currently a postdoctoral fellow at Beth Israel Deaconess Medical Center, Dr. Brake investigates the genetic regulation of tissue factor (F3) in hemostasis and cancer-associated thrombosis, while collaborating with the BioMe Biobank and aiming to eventually lead their own research lab.

Lay summary of funded research project: This project is the first to study humans with a genetic deficiency in tissue factor, which activates the first step in the formation of blood clots. The goal is to understand how this deficiency changes the baseline amounts of byproducts produced from the blood clotting pathway, and whether these individuals have an increased risk of bleeding.

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.

GENENTECH IN HEMOPHILIA

Genentech
A Member of the Roche Group

HTC

DAYTON CHILDREN'S HTC VISITS CAPITOL HILL

Every March, members of the bleeding disorder community from across the country meet in Washington, DC to advocate for our community. This NBDF-sponsored event is entitled "Washington Days" and allows volunteer advocates (patients, their families, HTC staff and chapter staff) to meet with their legislators and staff in person. Here, our community can share its stories and educate lawmakers about the very community they serve.

This year two of our HTC staff members were able to attend. Emma Boyd, MHA (program Manager) and Beth Linegang (Clinical Resource Nurse) met with Senator Bernie Moreno, and staffers from Representative Greg Landsman and Mike Turner 's offices. Alongside patients and families from the Cincinnati area, they were able to educate the legislators about Bleeding Disorders and discuss what they can do to better support the bleeding disorder community.

The issues discussed in meeting at the NBDF Washington Days 2025 are below:

- The Help Ensure Lower Patient (HELP) Copays Act, bipartisan legislation addressing abusive health plan/PBM practices that target high-cost medications and the patients who rely on them.
- Protect access to Medicaid, which provides essential health coverage for at least one third of the bleeding disorders community.
- Education on the federal hemophilia programs, which provide funding for multidisciplinary care at HTCs and for HTC surveillance and prevention activities in addition to outreach and education programs.
- Information and education related to women and girls with bleeding disorders was also incorporated into each of these three asks.

The HTC staff was proud to visit with legislators and to continue to advocate for our patients at a federal level. Advocacy experiences are available at the local, state and federal level. If you or a family member are interested in participating in advocacy activities or would like more information, please reach out to Emma Boyd at boyde2@childrensdayton.org.

Join the fight for a better future! NBDF Washington Days brings together advocates to push for federal funding and better access to care for inherited blood disorders.

American Medical ID

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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