

# BLOOD TIES

Tri-State Bleeding Disorder Foundation

| 635 W. Seventh Street

| Suite 407

| Cincinnati, OH 45203

1st Edition 2024



## Our Mission

Tri-State Bleeding Disorder Foundation is committed to improving the quality of life for patients and families living with bleeding disorders in the Greater Cincinnati, Northern Kentucky, and Southeastern Indiana communities.

Dear TSBDF Friends and Family,

This year I am turning 66 years old. When I was growing up in the early 1960's, the primary treatment for injuries such as knee or ankle bleeds was to wrap it in a bandage, put some ice on it, and elevate it by lying in bed or on the couch for a few weeks. Over the past 60 years, so many new products have been developed to not only treat bleeds, but also prevent them from happening in the first place. Even better than that, the research is continuing and I would even describe the progress as accelerating.

One way to find out about new products and treatments is to attend some of the events the Tri-State Bleeding Disorder Foundation provides throughout the year. My wife Vicki and I started attending these programs years before I became a member of the board of directors and I can tell you that some of the products we learned about as research projects are available today. The sponsors of the program provide these events at little or no cost to you and usually have an educational topic such as understanding insurance, physical fitness, or physical therapy as well as others which can be very informative and helpful.

Helen does a great job listing the future events on our website TSBDF.com, on our Facebook page, and in our weekly email newsletter so I'll just mention a few past events. Some of the restaurants we have visited are Montgomery Inn, Maggiano's Little Italy, Brio Italian Grill, and Cooper's Hawk just to name a few. The venues we have visited include Great Wolf Lodge, Kings Island, Great American Ballpark, Cincinnati Nature Center to see lighted trails in December, and this year we had a pickle ball event and celebrated World Hemophilia Day at Findlay Market which is an amazing Cincinnati icon.

Please be sure to watch for our notifications of events throughout the year and consider attending. You will no doubt learn something and enjoy yourself at the same time. If you are not receiving the weekly newsletter, email Helen at Helen@tsbdf.com and she can add you to the list.

Sincerely,  
Keith Peterson  
President  
TSBDF Board of Directors



## CONTENTS

- 2 President's Letter
- 3 Advocacy
- 3 Clot Control: A Story About Hemophilia
- 7 Ohio Statehouse Days
- 4 Great Wolf Lodge
- 8 Unite Walk 2024
- 9 TSBDF Front Porch Project and World Hemophilia Day
- 11 Helen Lamping Named ED
- 12 Patient Highlight: Joe Westling
- 12 Committee Spotlight: Program Committee
- 13 hC Bioscience Will Target Hemophilia A with Modified tRNA Therapy
- 14 Women Bleed Too
- 14 In Memory of Detrice Barry
- 15 2024 Calendar of Events

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# General Assembly Returns to Action Prior to Summer Recess

The Ohio General Assembly returned to Columbus earlier this month for a brief work period before summer recess and the November election season officially kick off. Lawmakers started their Spring work period with Governor DeWine's State of the State Address. In his annual speech, DeWine outlined several new child health initiatives including additional investments in school-based health clinics, the creation of a new children's vision strike force, and a pilot program for universal newborn home visiting in 11 counties. DeWine also called on lawmakers to pass a statewide ban on flavored tobacco products, enact legislation to make minor seatbelt violations a primary offense, and require schools to have a cell phone usage policy for students. While the Republican-controlled General Assembly is unlikely to embrace a statewide flavored tobacco ban or changes to Ohio's seatbelt laws, lawmakers are acting on DeWine's call for schools to adopt a cell phone policy by advancing House Bill 250.

The Ohio Bleeding Disorders Council recently held their Annual Statehouse Day on April 7th and met with dozens of lawmakers to advocate for our legislative priorities. Our top priority remains passage of House Bill 177, which is awaiting a floor vote in the Ohio House of Representatives. HB 177 was introduced last year by State Representative Susan Manchester (R-Waynesfield) and prohibits copy accumulator programs from being implemented by health plans. Under these programs, copy assistance is not counted towards a patient's deductible. A similar bill passed the House in the previous General Assembly but failed to clear the Senate. Should HB 177 receive a floor vote in the House before Summer Recess, it would face a similar fate in the Senate. We are also continuing to advocate for passage of House Bill 291 and House Bill 130. Sponsored by State Representatives Sara Carruthers (R-Hamilton) and Beth Liston, MD (D-Dublin), HB 291 prohibits non-medical changes to drug formularies during a plan year. HB 130, sponsored by State Senator Kevin Miller (R-Newark) would expedite prior authorizations for certain services. Both bills are pending in the House Insurance Committee

Lastly, we are starting to focus on next year's operating budget and preparing to meet with the DeWine Administration to discuss priorities. Our top budgetary goal is to continue raising the age of coverage for the Program for Children with Special Healthcare Needs (formerly the Children with Medical Handicaps program) under the Ohio Department of Health to age 26; we have successfully raised the age over the past two budgets from 21 to 25 and secured funding to cover this population. We are also focused on Ohio Medicaid and hope to preserve stable funding for the future. Medicaid is the single largest expenditure in the state budget and lawmakers often raise concerns over increased spending on the program; state Medicaid expenditures have nearly doubled over the past decade, largely due to the expansion of coverage to adults under the Affordable Care Act. We are also planning to discuss drug coverage with the Ohio Department of Medicaid in the near future as it has been several years since the preferred drug list for Medicaid was updated. Thank you to everyone who attended OBDC Statehouse Day and for your continued advocacy!

BY DANNY HURLEY, OBDC

The Ohio Bleeding Disorders Council recently held their Annual Statehouse Day on April 7th and met with dozens of lawmakers to advocate for our legislative priorities.

## Clot Control: A Story About Hemophilia

Cincinnati Children's Hemophilia Treatment Center (HTC) team and Media Lab artists recently partnered to develop a 3D animated video on hemophilia. The purpose of this video, Clot Control: A Story About Hemophilia, is to improve the understanding of hemophilia for a pediatric audience. This video focuses on topics of preventative care, such as recognizing the signs of a bleed, getting regular comprehensive care, and safe sports and physical activity. "The video explains the parts of the blood and what happens in the blood when someone with hemophilia is injured", says Lisa Littner, Cincinnati Children's HTC Program Manager. "We also explain what inhibitors are, since that is a harder concept for people to understand."

Clot Control is written at the 7th-grade reading level so that it can appeal to all health literacy levels. It is available in English and Spanish, on Cincinnati Children's YouTube Channel. Lisa has shared the video through presentations to HTC staff at a regional meeting and more recently has had the opportunity to share the video with national and international audiences at conferences. "Our team hopes that by sharing the Clot Control video with other HTC staff, those staff can share this video with their patients and families, and more people can learn about hemophilia."

If you have not seen the video yet. Scan the QR code or click [here](#).

BY LISA LITNER





Coyote Canyon ... Alberta Falls ... Fort Mackenzie. No, those are not locations on a map leading to buried treasure in the Wild West. Those are just a few of the slides and attractions that over 170 members of our TSBDF community got to enjoy at TSBDF's Family Education Conference at Great Wolf Lodge on February 24, 2024. But it wasn't all just fun and games. There were lots of helpful presentations throughout the conference for both adults and kids, along with time to meet with our sponsors and hang out with old and new friends alike.

The day started with a presentation by Dr. Cristina Tarango from Cincinnati Children's Hospital Medical Center (CCHMC) on upcoming therapies for various bleeding disorders. This included information about gene therapy for both Hemophilia A and Hemophilia B, along with some potential new treatments for Von Willebrand disease. Trying out a new treatment can be a bit intimidating for patients and their families, so it was great to get information about these new possibilities directly from Dr. Tarango.

The next speaker was Angie Blue from the Hemophilia Alliance. Angie provided great information about the Hemophilia Alliance, including what it is and how they help Hemophilia Treatment Centers. Over the past 25 years since they were founded, they have given over \$8 million in grants back to the community! This presentation also included members of the CCHMC HTC staff to highlight some of the improvements they have made recently. For example, the HTC staff has been working with the Emergency Department (ED) at CCHMC since 2017 to reduce the time from a patient's arrival in the ED to the time they receive factor. On behalf of all their patients and caregivers, I have to say "Thank you!" This is a big issue for us, and we really appreciate your help!

The afternoon sessions started with a presentation by Lisa Littner from the CCHMC HTC about navigating the health care system. Lisa provided tips for dealing with the ED and talked about how finding out your own personal learning style can help you better understand what your provider is saying during your visits. This can be a challenge for all patients, not just those with bleeding disorders. So, I thought this session was particularly helpful.

The final general session of the day was with Dr. Shayla M. Bergmann from Novo Nordisk. Dr. Bergmann provided insights regarding how pain can impact members of the bleeding disorder community and some helpful suggestions on ways to handle it.

The presentations wrapped up with breakout sessions for men with bleeding disorders, women with bleeding disorders and parents/caretakers. We attended the session for parents/caretakers that focused on stressors and the importance of self care.

While we were attending these sessions, the kids were divided into various age groups and attended their own educational sessions. Our kids really liked the yoga session (the fact they got their own yoga mat was a big plus). 😊

At the end of the day, the families were free to enjoy the waterpark and all the other amenities at Great Wolf Lodge. Of course, such a great event wouldn't be possible without the hard work of the TSBDF staff and our fantastic sponsors.

Thanks to all of you for another fantastic conference. We had an absolute blast and can't wait for the next one in 2026.

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*Thank you!*





**Zollinger Family**



**Dr. Cristina Tarango**



**Mike & Lindsay Schulte**



**Dental Education Session**



**Braxton & Elliott**



**Brynn S**



**Dental Session**



# MORE! Great Wolf Lodge



**Braxton and Elliott**



**Morriss Family**



**Capone Family**



**Wound Care**



**Edwards Family**



**Yoga!**

# Ohio Statehouse Days

BY TIFFANY WEIGLE



In April 9, 2024, my family and I had the privilege of attending the Statehouse Day organized by the Ohio Bleeding Disorders Council (OBDC). This annual event serves as a platform for Ohioans affected by bleeding disorders to engage with their state elected officials and advocate for issues crucial to our community. The primary goal is to raise awareness and advocate for improved care and support. This year, we had the opportunity to connect with elected officials and share personal stories in support of House Bill (HB) 177 (Copay Accumulator Prohibition), HB 291 (Non-Medical Switching Prohibition), and HB 130 (Prior Authorization Gold Card).

Participating in OBDC's Statehouse Day was an incredibly rewarding experience for my family, especially considering our

connection to the bleeding disorder community through our two-year-old son, Jack, who was diagnosed with severe Hemophilia B just two days after birth. As newcomers to this community, we have been deeply touched by its warmth and support. Statehouse Day further solidified our connection and commitment to advocating for better policies and resources.

Having previously worked as a Congressional intern, I understood the power of personal stories in influencing elected officials. It was heartening to witness how well-represented the bleeding disorders community is in Ohio's legislature and the strong relationships OBDC has cultivated over the years.

Thanks to OBDC's advocacy efforts, we had meaningful meetings with several elected officials and their staff. We also shared a luncheon with officials who couldn't accommodate formal meetings, and it was heartwarming to see many of them wearing red ties in solidarity with our community.

Despite our community's relatively small size in Ohio, I was impressed by the impact we've made compared to larger advocacy groups. During our discussions about the advocated bills, we highlighted how these measures would not only benefit those with bleeding disorders but also individuals with various chronic medical conditions. It was a proud moment to realize that our efforts could have far-reaching benefits beyond our immediate community.

As is typical with events in the bleeding disorder community, connecting with other families was a highlight. Meeting families from across Ohio, sharing stories, and learning from those further along in their Hemophilia journey was incredibly enriching. We're already looking forward to making OBDC Statehouse Day a cherished family tradition.

For those considering participation in the future, I highly recommend it. You don't need a background in politics or an in-depth understanding of legislative processes. OBDC offers straightforward training and resources to support your engagement. The only requirement is a willingness to connect with others and share your story.

## More Ohio Statehouse Days

BY JEN LOVING

Our family has been attending OBDC's Ohio Statehouse days since our son, Jackson, was young enough to be put in a stroller, he is 16 years old now! We find incredible value in attending Statehouse Days as it allows us to meet with our Senators/Representatives and tell them our story. To share our struggles with them so they know what we go through and remember us whenever an issue comes up for discussion or a vote. We volunteer our family to be their expert in bleeding disorders so that if they have questions they know they can contact us. Statehouse Days is important for us to attend so that we can be the voice of the Bleeding Disorder community when others in our community can't be there or are unable to share their story. Statehouse Days is building relationships with our lawmakers so they have a face to put with a community. So that we, as the Bleeding Disorder Community are not forgotten. I encourage you to attend next year! Help us make an even bigger impact!





# 7th Annual Unite for Bleeding Disorders Walk

Join us on Saturday, August 17, 2024, at Mt. Echo Park  
(202 Crestline Drive, Cincinnati, OH 45202) for TSBDF's Unite Walk!

Unite for Bleeding Disorders is a nationwide event that raises funds and awareness for all bleeding disorders. Participants raise money, locally and nationally, for crucial research, advocacy, and education by joining together in a fun and festive event.

According to the National Bleeding Disorders Foundation, participants raise \$120 on average. This year participants must raise a minimum of \$25 by July 19th in order to receive the exclusive Unite t-shirt.

Teams account for about 80% of the monies raised in walks. They represent companies, organizations, families, schools and clubs, and can range from as few as five walkers to hundreds. Forming teams is a great way to build company morale and camaraderie among co-workers. Families and friends can join together to walk for a common cause and increase community spirit (a family friend event – bring strollers!).

100% of the funds raised will support TSBDF's efforts in advocacy, education, and research initiatives!

Choose from the prizes below based on how much you fundraise. A prize redemption form will be emailed to you. Choose from the prizes below based on how much you fundraise. A prize redemption form will be emailed to you. The items will be mailed to your preferred address.

*\$1000-Backpack Cooler      \$1000-Blue Tooth Speaker*  
*\$500-\$999-Phone Charger Stand w/Mini Fan*  
*\$500-\$999-Dog Leash      \$250-\$499-Belt Bag*  
*\$250-\$499-Lunch Bag Cooler*

Individuals that raise \$500 or more are part of The Factor Club and will receive a medal during the awards ceremony.

To register go to <https://www.uniteforbleedingdisorders.org/index.cfm?fuseaction=donorDrive.event&eventID=943>  
Questions? Contact Lisa Raterman at 513.961.4366 or email [cincinnatiisinmyblood@gmail.com](mailto:cincinnatiisinmyblood@gmail.com)



# TSBDF Front Porch Project and World Hemophilia Day

TSBDF celebrated World Hemophilia Day with TSBDF's 5th Annual Front Porch Photo Project! Our photographer **Teresa Ripley** drove from house to house to get photos of our bleeding disorder families on their front porches wearing red in support of World Hemophilia Day.

Cincinnati and Northern Kentucky lit up red in honor of World Hemophilia Day this year! The Duke Energy Convention Center sign, First National Bank, The CCHMC's Resource Center and The Radisson in Covington lit up red to show their support of the TSBDF bleeding disorder community!



**WORLD HEMOPHILIA DAY**  
17 APRIL



**Ficklin Boys**



**Shade Boys**



**Ficklin Family**



**Shade Family**





**Flick Family**



**Long Boys**



**Long Family**



**Jack**



**Weigle Family**



**Anderson Family**



**Mitchell Family**



**Gabe**



# Helen Lamping Becomes TSBDF's Executive Director

By Lisa Littner

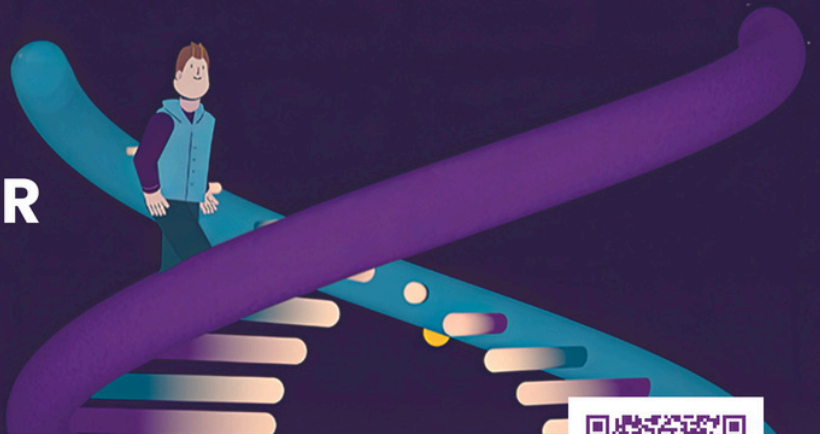
Helen Lamping transitioned to TSBDF's Executive Director in 2023 and formally started her new role earlier this year. Helen has worked with TSBDF since 2007 and she is excited to continue to grow in her career in her new role. During her time with TSBDF, Helen has seen many of the areas of the organization grow and she has led many of these changes. "I have been involved in the expansion of our support programs, ensuring that individuals living with bleeding disorders and their families have access to a wide range of resources, including educational materials, financial assistance, and peer support networks. I've helped foster collaborative partnerships with the local HTC's to help promote awareness and develop better educational and support programming. We've also worked to collaborate more with the other chapters in Ohio to bring more opportunities to our members", says Helen.

As Helen thinks about the future of TSBDF, she would like to continue to raise awareness by educating the public about bleeding disorders and their impact on individuals and families. She would also like to highlight the resources that are available for support and treatment. "I think it's important to foster a sense of community and belonging among people with a bleeding disorder and their families through events, support groups, and other outreach initiatives. Living with a rare medical condition like a bleeding disorder can be isolating. Our goal at TSBDF is to give patients and their families a community that understands and supports them," says Helen.

**Congratulations Helen on your new role! We are excited about your continued involvement and support in the bleeding disorders community.**



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# Patient Highlight

By Joe Westling

Growing up with Type III VWD was a challenge. The fear of “what do we do” was ever present when a situation arose. Being an active child in sports, not being able to do the same activities as my friends was hard to deal with. It created anger and sadness. Within the TSBDF, my family found strength and support—a community that understood the challenges. This is a disorder that can make you feel alone. Having the foundation's support was such a relief. Whether it was attending summer camps, participating in educational workshops, or simply bonding over shared experiences, the foundation provided a sense of normalcy.

My wife, Amy and myself have become more active members since having our daughter, Sofia. She is now 2. Knowing she will have to face the same challenges I did, breaks me. It is our goal to not let type III VWD define her as a person. Having Amy's support, the TSBDF, Cincinnati Children's— is reassuring knowing she has the best care afforded to her.

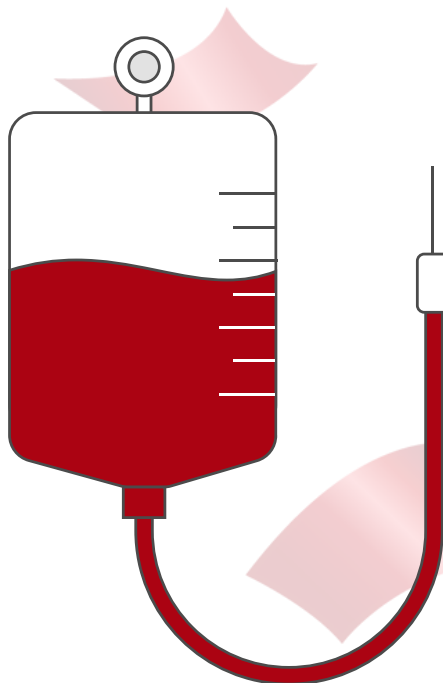
Looking back, reaching out more would have been beneficial. The foundation is growing and there is more support now than ever before. To the parents/children out there navigating this, know that you are not alone in this. It doesn't have to be as daunting as it feels. Reach out. Even if it's just to have a conversation, it truly helps.

Please reach out to me anytime. 859-757-3520 or xujoe711@gmail.com - *Amy, Joe, Sofia*



# TSBDF Program Committee

By Julie Hendrickson



Did you ever wonder how TSBDF goes about deciding what programs to offer to patients and families? Well, wonder no more.

TSBDF has a program committee that is comprised of patients, families, HTC providers, TSBDF staff, and board members. The committee meets monthly. They discuss what went well and what could have gone better, if anything, with past programming. The committee plans future events and brainstorms about new programming that might draw interest from the bleeding disorder community, while meeting their unique needs. Including patients and families in the program planning process is vital to its success. Who knows what educational gaps exist and what needs are unmet amongst the community better than the patients and their families, no one!

Shortly after I was asked to join the program committee, a couple members made it clear that learning how to perform factor infusions for their children was a priority to them and other members of the bleeding disorder community. Discussion began amongst the committee members and the logistics of this program were discussed with the local HTCs (both UC and Cincinnati Children's). After several months of planning, a successful infusion teaching event took place that combined learning and fun. This type of programming is just one example of the important work that takes place.

# hC Bioscience Will Target Hemophilia A with Modified tRNA Therapy

*Reprinted from NBDF Newsbrief  
Inside Precision Medicine  
April 23, 2024*

Boston-based hC Bioscience will target specific forms of hemophilia A with its lead candidate therapy, HCB-101, an anticodon engineered transfer (t)RNA.

The company announced this week at the World Federation of Hemophilia 2024 World Congress in Madrid that they would be targeting the blood condition and that preclinical results for the candidate therapy, which restores full-length factor VIII, were encouraging.

Although therapies and vaccines based on messenger RNA (mRNA) and RNA interference (RNAi), such as those developed by BioNTech, Moderna, and Alnylam, as well as a number of antisense oligonucleotides (ASOs) have all successfully reached the clinic and have been approved, tRNA-based therapies are still in early development.

hC Bioscience is one of several companies exploring the potential of this new type of molecular medicine. It is developing two platforms. The first “Patch” platform, which it is using for its lead candidate, uses tRNA to restore the function of proteins that have been prematurely shortened due to genetic mutations that stop the end of the protein being fully translated known as premature termination codons (PTCs).

The second “Switch” platform allows the targeting of diseases caused by unwanted proteins. Using this method, a disease-causing protein can be marked for destruction during translation. The science was based on work on tRNAs performed by Christopher Ahern, PhD, and John Lueck, PhD.

Hemophilia A is a blood clotting disorder characterized by a genetic abnormality in the function of clotting factor VIII, as opposed to hemophilia B, which is caused by a deficiency in the activity of clotting factor IX. Around 400 babies in the U.S. are born with this condition each year. The affected genes are on the X chromosome and inheritance is recessive so the large majority of people with hemophilia are biologically male, although females can occasionally be affected.

There are a variety of different mutations that cause hemophilia A. Of these, around 20 percent are caused by a PTC that results in a shortened, non-functional version of the factor VIII protein. hC Bioscience is using its Patch platform to overwrite the genetic mutation that causes the shortened protein.

HCB-101 is a modified tRNA that is delivered to the liver, where factor VIII is produced, in a lipid nanoparticle. The candidate therapy has yet to enter human trials, but the company has produced a full-length protein in the lab using this technique and has successfully targeted the liver with the therapy in a mouse model.

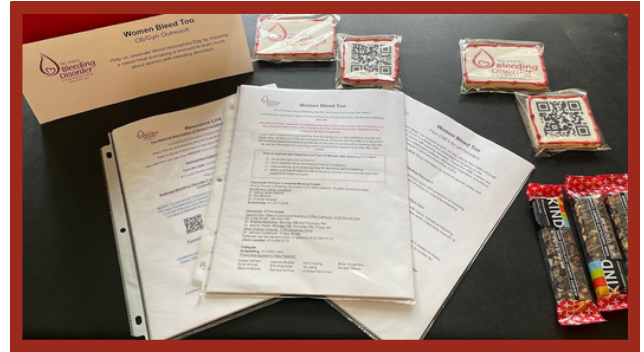
“We’re excited to develop tRNA-based protein editing as a potential new breakthrough treatment option for patients with severe hemophilia A. Our lead program is on track to rapidly move into the clinic, where we hope to establish our novel protein editing approach as an easily adaptable modality across a broad spectrum of genetically defined diseases,” said Leslie Williams, CEO of hC Bioscience.

“Because our therapies are gene agnostic, the engineered tRNA that reads through PTCs in hemophilia will recognize the same PTC in the context of hundreds of other genetic disorders as well. We see tRNAs as not just a novel modality, but a powerful, universal drug development platform that expands the potential of genomic medicine to improve the lives of patients.”



# Women Bleed Too

The Women Bleed Too project is a collaborative outreach program with CCHMC HTC, UC HTC, TriHealth Hematology, and TSBDF to educate OB/GYN practices on women with bleeding disorders. The focus of this program will be early, accurate diagnosis for women. Women with bleeding disorders have been historically underdiagnosed and undertreated. Their bleeding disorder symptoms are often not recognized as being abnormal. As a result, women with bleeding symptoms can experience a delay in diagnosis. Having a correct and timely diagnosis is critical in ensuring the appropriate medical care for women with bleeding disorders.



We have identified the different OB/GYN practices in our region to deliver educational materials and treats. The treats consist of cookies made by Amy's Cookies with a working QR code that links to education along with the TSBDF logo!

We will also offer CME programs at no cost to all OB/GYN providers in collaboration with Hemophilia Federation of America (HFA) and the CDC. The CME programs will be offered in the 3rd quarter of 2024 and will be a series of four, live, one-hour presentations. The topics are as follows: How to Screen for a Bleeding Disorder, Testing for a Bleeding Disorder, Iron Deficiency, and Building a Bridge with Specialty Care.



The Women Bleed Too project's goal is to increase the knowledge and understanding of bleeding disorders among Obstetrician/Gynecologists in the Greater Cincinnati/NKY area. This increase in knowledge will result in women with bleeding disorders receiving a prompt and correct diagnosis and will improve access to care for women. This project is made possible by a grant from the Hemophilia Alliance Foundation!

## In Memory of Detrice Barry

BY EDDIE CALDWELL

Detrice Green Barry, age 58, passed away the evening of Monday, January 15, 2024 at Hawthorn Glen Nursing Home. She was born to the late Roosevelt and Ethel Ray (Covin) Green on September 24, 1965 in Albany, GA. Detrice was a loving and devoted mother to her boys, Denis Jr and Anthony Barry. She was a long time resident of Mason, Ohio. She earned multiple degrees including a PhD and was a Nursing Professor at Wright State University.

Detrice was heavily involved in the Hemophilia community. She regularly attended NHF, HFA, and FAMOHIO events over the years. She was an active member of the Ohio Nurses Association and a devoted member of the AKA Sorority.

Detrice was an active Board of Director during 2012 -2016 for the Tri-State Bleeding Disorder. She was a remarkable advocate of the Greater Cincinnati Bleeding Community and left a lasting impact on the community and everyone she met. Her can-do spirit of activism, hope and drive will live on in the people she touched. Detrice's vision was to focus on creating free services for individuals and families impacted by bleeding disorders provided by the foundation. Her two sons both with severe hemophilia A and now young adults are benefactors of the advocacy and the work that Detrice sponsored and supported.

Detrice is survived by her sons Denis (fiancé Lexy Benjamin) Barry Jr, Anthony (fiancé Rachel Simon) Barry; two sisters Carletha Gates, Darlene Trice, multiple nieces/nephews, and many longtime family friends and colleagues.



Save  
the date!

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2024  
Conference  
August 9 - 11**

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**WHAM!**

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## CALENDAR OF EVENTS

### 2024 EVENTS

**June 22nd**

TSBDF Family Education Day @ Kings Island

**July 14th-26th**

Camp NJoyItAll

**August 9th-11th**

FAMOHIO

**August 17th**

Unite for Bleeding Disorders Walk at Mt Echo Park

**September 12th-14th**

NBDF Bleeding Disorders Conference

**November 6th**

Ask the Doc/Annual Meeting @The Graduate Hotel

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