The Loop

STAY IN THE LOOP WITH OUR NEWSLETTER FOR THE BLEEDING DISORDERS COMMUNITY & FRIENDS



Camp Black & Blue 21st Annual Gala

2026: ISSUE 2

GOBDF
GREATER OHIO BLEEDING DISORDERS FOUNDATION

OUR MISSION

To enhance the quality of life for people with bleeding disorders & their families through advocacy, education, research, and other constituency services.

In The Loop

with our executive director

Tanya Stewart

2026: Issue 2

As I reflect on this edition of The Loop, I am struck by the incredible strength, resilience, and leadership demonstrated throughout our community. And while many of the stories in these pages center on the experiences of women, the themes they carry are universal: perseverance, advocacy, connection, and hope.

For generations, women have played a vital role in caring for families, advancing healthcare, and building stronger communities. Inside the bleeding disorders community, that truth runs especially deep. Their most important contributions often happen quietly — in waiting rooms, at kitchen tables, on the phone with insurance companies — yet their impact is profound and lasting.

This issue celebrates several of those women. Anne Goodman opens up about her journey navigating grief, diagnosis, and advocacy as both a patient and a mother. Our community gathered on the waters of Lake Erie for a meaningful afternoon aboard the Lady Caroline, where national leaders from NBDF joined us to explore what inclusive research for women with bleeding disorders really looks like. And our Bloom Women and Teens Retreat reminded us once again how powerful it is when women and girls show up authentically for one another.

We also want to make sure you do not miss the important clinical information shared by Irene Boehlefeld of Akron Children's Hospital HTC. Her article on heavy menstrual bleeding and bleeding disorders in women and girls is one every family in our community should read.

This issue is a reminder that our community is strongest when every voice is heard and every experience is valued. Thank you for being part of this journey — whether you are a patient, caregiver, healthcare partner, volunteer, donor, or advocate. Your commitment helps create a more connected and supportive future for everyone we serve.

With gratitude,

Tanya Stewart



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THANK YOU TO OUR CONTRIBUTING AUTHORS & PHOTOGRAPHERS

Authors: GOBDF Staff & Irene Boehlefeld, BSN, RN-BC, CPHON
Photographers: GOBDF Staff & Charles Corbett

Scan for Community Resources

Camp BLACK & BLUE

Some evenings leave a lasting mark. Our Camp Black and Blue Ball was one of them.

From the moment guests arrived, they stepped into an atmosphere that felt both warm and special. Rustic touches — wood accents, soft greenery, warm lighting — created a setting that was cozy and elegant at the same time. It was the kind of space that made people want to linger, connect, and be present. And that is exactly what they did.

The night was filled with energy from start to finish. The bottle pull sold out faster than ever, drawing excited crowds and keeping the momentum going all evening. The auction and raffle items were equally impressive, sparking friendly competition and enthusiastic bidding. Every contribution — no matter the size — added to something much bigger than the sum of its parts.

The most meaningful moments of the night came when the room went quiet to listen. We were honored to welcome Liv from Flying Horse Farms and Rachel, a longtime camper and beloved member of our GOBDF community. Their stories were honest, heartfelt, and deeply moving. Hearing firsthand how camp builds confidence, independence, and joy in children facing serious health challenges reminded everyone in the room exactly why they came. It was a pause that grounded the whole evening in its true purpose.

And that purpose is real. Because of the generosity shown that night, more children will get to experience what Flying Horse Farms makes possible — the campfire laughs, the new friendships, the freedom to just be a kid in a place built with them in mind.

What made Camp Black and Blue truly unforgettable, though, was not any single moment. It was the feeling that ran through all of them. The laughter over cocktails. The quiet conversations between old friends and new ones. The shared enthusiasm for a cause that genuinely matters. The room was full of people who showed up not just to have a good time, but to make a difference — and they did.

To everyone who attended, donated, and believed in this mission: thank you. The night was a success in every sense. More importantly, it was a meaningful step forward for the children and families we are proud to serve.♥

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A Night to Remember









BLACK & BLUE BALL
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THANK YOU FOR YOUR SUPPORT

Community Friends Spotlight



Anne Goodman, MPH
The Voice Behind the Journey

"Grief is not a problem to be fixed. It is a sign of love, of connection, of being deeply human."

You may have heard Anne Goodman's name in connection with her work as a Certified Grief Recovery Specialist® — but her path to that work began right here in the bleeding disorder community. Anne was diagnosed with Von Willebrand Disease at 45, after decades of symptoms dismissed as normal. Her daughter Rachel was diagnosed at eight, following a life-threatening hemorrhage after a routine tonsillectomy.

That experience — the years of unanswered questions, the fear, the relief and grief that arrived together — transformed Anne into one of the most passionate advocates in our community. Today, she helps others navigate the emotional complexity of chronic illness, offering one-on-one grief support, group programs, and a perspective shaped by lived experience.

Anne's message to our community is simple: your grief is valid, and you do not have to carry it alone.

Let's get together to talk about IXINITY®

As a woman and mother to children with bleeding disorders, I am committed to this community through all seasons of life. Having seen the challenges families face, I strive to foster support, understanding, and inclusion.

Becca Robbins,
Hemophilia Territory Manager
Midwest Region



Contact Becca at 479-685-2532 or becca.robbins@medexus.com

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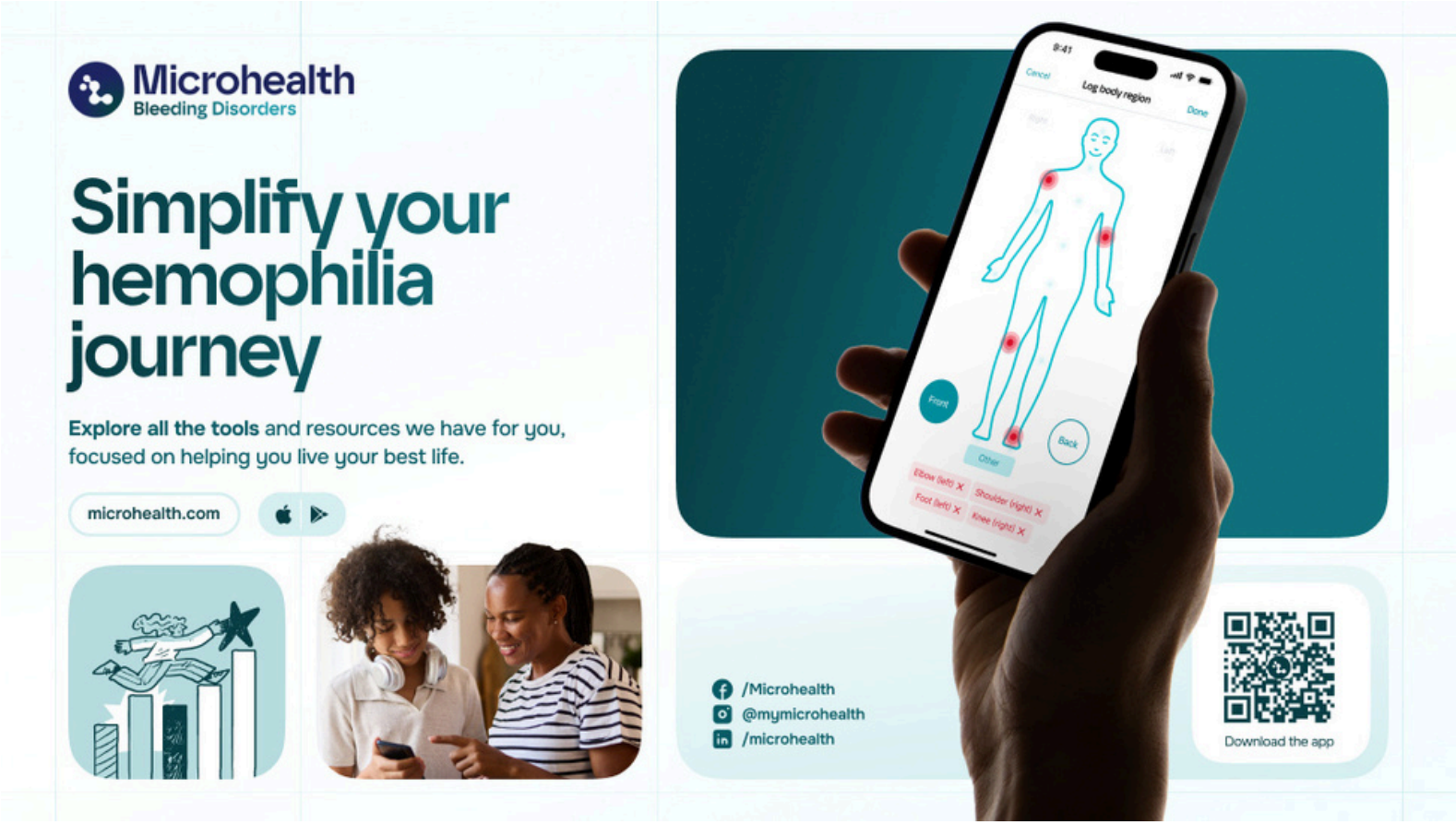


Your Voice at the Statehouse



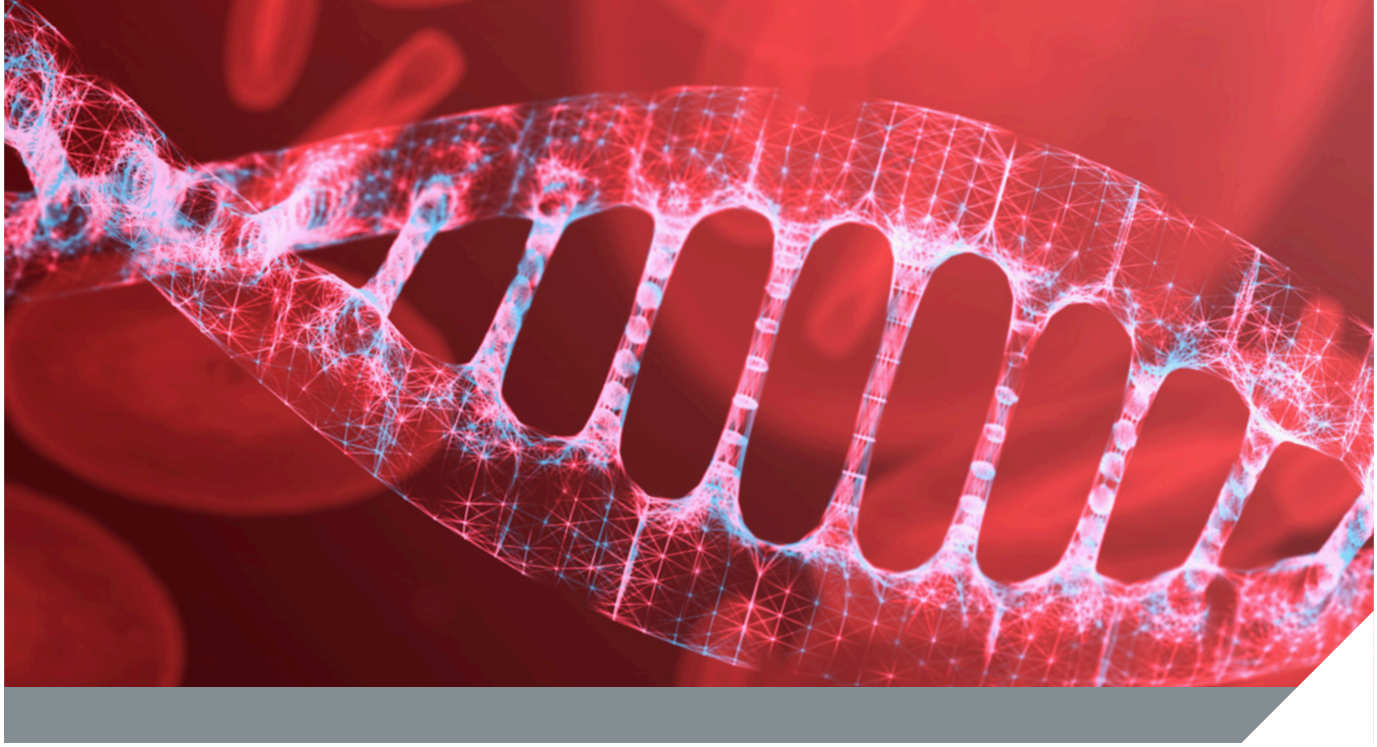
On March 25, advocates from across Ohio came together for the annual Ohio Bleeding Disorders Council Statehouse Day — and they showed up ready to make an impact.

In person, our advocates attended 23 legislative appointments, sharing educational information about bleeding disorders and the very real financial burden patients face. They also handed out more than 100 cookies along the way , because serious conversations seem easier with a bit of sugar.

This year, advocacy extended beyond Columbus. Thanks to an action alert from the Hemophilia Federation of America, more than 50 people joined remotely by emailing lawmakers directly.

A key focus this year was Senate Bill 207, which would ban copay accumulators in Ohio — a practice that forces patients to pay high out-of-pocket costs even when they have copay assistance. Similar bills have already passed in 26 states, Puerto Rico, and Washington D.C.

The work is not done. Watch for future action alerts and get involved. If copay assistance is essential to your access to treatment, reach out to chair@ohiobdc.org to learn how you can help.



Bleeding and Clotting Disorders Center at the OSUCCC - James

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The James

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BLOOM Women & Teens Retreat: Rooted in Community

Nestled in the peaceful setting of Hocking Hills Lodge and Conference Center, our spring Bloom Retreat offered something our community deeply deserves — space to breathe, connect, and simply be.

From Friday evening firepits and handmade sun catchers to Saturday morning hikes, yoga, and honest conversation, every moment of the weekend was thoughtfully designed for the women and teen girls in our bleeding disorder community.

We were grateful to welcome Colleen Joiner of Cascade Hemophilia Consortium, whose facilitation brought creativity and energy to the group, and Samara Linnell, RN, of The Ohio State University Wexner Medical Center, who provided expert guidance on care and treatment for women with bleeding disorders.

The weekend was filled with laughter, learning, and the kind of connection that reminds us why community matters. Thank you to every woman and teen who showed up authentically and made Bloom so special.

We cannot wait to do it again.

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Cleveland Shoreline, Common Ground

On May 9, more than 100 members of the GOBDF community came together aboard the Lady Caroline for a Mother's Day Luncheon Cruise along Cleveland's waterfront — and the afternoon delivered on every level.

The setting was beautiful. The company was even better. But the highlight of the day was a powerful featured presentation — "Women Bleed Too: Looking at Women in Research" — led by **Samantha A. Carlson, Director of Research at the National Bleeding Disorders Foundation (NBDF)**. Her insights sparked honest, important conversation about the need for more inclusive research and greater representation of women's experiences in the bleeding disorders community.

We were also honored to welcome **Lauren Mlack of NBDF** — making this a rare and meaningful occasion with two national representatives present. Having that level of support in the room, alongside our local community, was a powerful reminder of the partnership between NBDF and GOBDF and of their shared commitment to advancing care and awareness for women with bleeding disorders.

Together, these voices reinforced something our community already knows: when women gather, share, and speak up — things change.

Thank you to everyone who joined us for a day that was as meaningful as it was memorable.

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HTC CORNER

Bleeding disorders are often thought of as conditions that primarily affect males, particularly hemophilia. However, women and girls can also be affected — and bleeding can significantly impact their reproductive health and daily life.

The most common bleeding symptom in females is heavy menstrual bleeding, also called menorrhagia. Signs include:

- Bleeding that lasts more than 7 days
- Periods more frequent than every 21 days
- Soaking through a pad or tampon every 1–2 hours or less on the heaviest days
- Flooding or gushing that affects daily activities or school and work attendance
- Passing blood clots larger than a quarter

Untreated, prolonged bleeding can cause iron deficiency and anemia — a condition that occurs when the blood does not have enough healthy red blood cells to carry oxygen throughout the body.

Symptoms of anemia may include: fatigue, weakness, or dizziness; pale skin; increased thirst; moodiness; pica (craving non-food items like ice or dirt); fast heartbeat; shortness of breath; cold hands and feet; brittle nails; and poor appetite.

Left untreated, anemia can lead to attention difficulties, depression, increased risk of infection, delayed growth and development, and an enlarged heart.

The good news is that effective treatments are available. The challenge, however, is determining whether heavy menstrual bleeding is related to a bleeding disorder or another cause. That is why Akron Children's established a multidisciplinary clinic where undiagnosed patients meet with both a hematologist and an adolescent medicine specialist in a single visit. Together, they work to identify the cause and develop an individualized treatment plan.

Akron Children's has offered this specialized clinic since 2010 and is designated as a Women and Girls with Bleeding Disorders Clinic of Excellence. The hospital is also a member of the Foundation for Women and Girls with Blood Disorders Learning Action Network.

If you or someone you love experiences heavy menstrual bleeding and is under 21, contact the Akron Children's HTC clinic for more information or to schedule an appointment. For patients 21 and older, please reach out to one of the adult HTC providers in your area. 🧡

IRENE BOEHLEFELD, BSN, RN-BC, CPHON PROGRAM COORDINATOR, AKRON CHILDREN'S HOSPITAL HTC



More childhood, please.®



What makes us special is the care we give to children with conditions like bleeding disorders.

We're here for them every step of the way—from teaching and planning surgeries to making sure the transition from kids' care to adult care is easy.

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Nationwide Children's Hospital
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Please visit our website by scanning the QR code for the most updated information and event details

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