BLOOD TIES

Tri-State Bleeding Disorder Foundation | 635 W. Seventh Street | Suite 407 | Cincinnati, OH 45203

2nd Edition 2025

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.

Greetings TSBDF Friends and Family,

TSBDF has done a tremendous amount of work in the second and third quarters of 2025. Most notably, we operationalized another Camp "Njoyitall" and awarded $10,000 in scholarships to some well deserving applicants.We also added Denis (Drew) Barry Jr to the Board of Directors. We welcome Drew to the team as he continues the work of his late mother, Detrice (active in TSBDF for many years) in making life better for those with bleeding disorders. We look forward to working with Drew moving forward.

Our 8th annual Unite Walk was held on Saturday, August 16th at Mt. Echo Park. The Event was extremely successful, and we were able to raise nearly $29,000. We want to thank everyone who participated and/or donated to this year's walk. All funds raised go directly to support important chapter programs and services. Please keep next year's Unite Walk top of mind as we move into 2026.

I encourage you to get involved with our team at TSBDF. One of the best ways to get involved, without commitment to a Board of Directors position, is to sit in with one of our committees. The advocacy committee discusses/plans strategy related to issues surrounding the Bleeding Disorder community. The Development Committee manages the fundraising plan for the chapter to include grants, sponsorship and donations. The Finance Committee manages the budget and financial reporting. Finally, the program committee plans all educational and social events. Find the committee that best matches your skills and experience. If interested, please contact the chapter office and our team can help you navigate the process.

Finally, we also encourage you to share our information with your network of friends and family. Donating to The Tri-State Bleeding Disorder Foundation is as simple as going to TSBDF.com and clicking the big, red, DONATE button in the top right corner of the page. All gifts help us to continue to provide emergency patient aid, education, advocacy and other services to the Bleeding Disorder Community.

As we head into 2026, the Board of Directors would like to wish you and your family Happy Holidays and a prosperous New Year.

Sincerely,

Scott Daniels
President
TSBDF Board of Directors

CONTENTS

Advocacy Updates - Open Enrollment

BY RANDI CLITES

Open Enrollment. These two words cause a lot of anxiety for our bleeding disorders community. Whether you are waiting on enrollment information from your employer, Medicaid or Medicare, or the ACA Marketplace, or you have it and are trying to make the coverage decision for 2026, it is a challenging time. Please know there are resources to help you decide for your 2026 plan year. The National Bleeding Disorders Foundation has updated the insurance toolkit. You can visit https://www.bleeding.org/bleeding-disorders-a-z/healthcare-coverage/personal-health-insurance-toolkit to help you make decisions on which plan to choose.

Also, if you see a big spike in your premiums or out-of-pocket costs, please reach out to the chapter for resources to help with that financial burden. There is a state program through the Ohio Department of Health called Complex Medical Help. Bleeding disorders are covered; the program is a great safety net program to help pay for the costs not covered by your primary insurance coverage. There is also a program to help pay your portion of premiums for adults over 26 with hemophilia. Contact your HTC Social Worker for both of these programs.

The Ohio Statehouse continues to be busy with bills impacting our community. There are three bills the Ohio Bleeding Disorder Council is watching: SB207 to ban copay diversion programs, HB257 to address negative impacts of medical debt, and two bills to streamline prior authorization process HB212 and HB220. If you would like to engage in advocacy at the Statehouse, a Save the Date will be coming out soon for Statehouse Day 2026.

Research Corner

Treatment Products for Bleeding Disorders - Novel Agents

BY RALPH GRUPPO, M.D.

Today, the treatment for bleeding disorders is vastly different from what it was even a few years ago. New products and innovative approaches to treatment continue to offer a wide array of choices for persons with bleeding disorders. No longer based on the traditional replacement of clotting factor, designer antibodies and innovative molecules offer freedom from bleeding episodes with manageable adverse side effects. Some of these newer therapies briefly discussed in this article include the novel agents in development (Sutacimig and HMB-002) and recently FDA-approved blood clotting rebalancing agents (Alhemo, Qfitlia, and Hympavzi).

NOVEL AGENTS IN DEVELOPMENT

Sutacimig – a novel new potential therapy for a severe inherited platelet disorder. Sutacimig has been developed and is being studied by Hemab Therapeutics in clinical trials as a new potential treatment for Glanzmann thrombasthenia. Glanzmann thrombasthenia (GT) is an ultra-rare inherited bleeding disorder that is characterized by poorly functioning platelets due to a particular protein deficiency which results in inadequate clotting and increased susceptibility to bleeding. People with GT may experience mild-to-severe bleeding symptoms, some of which can be life threatening if not promptly treated.

Existing therapies employed to treat bleeding associated with GT include platelet transfusions and recombinant factor VIIa. While these therapies are primarily used to treat bleeding events as they arise, Sutacimig is designed to be a preventive therapy. Sutacimig is a bioengineered antibody that binds, stabilizes, and "recruits" the important coagulation protein FVlla to the site of activated platelets at the location of a vascular injury to form a clot.

Hemab Therapeutics recently presented their clinical and preclinical data at the Congress of the International Society on Thrombosis and Haemostasis (ISTH) in Washington, DC in June of this year. The phase 2 trial data indicated that Sutacimig treatment demonstrated more than a 50% reduction in the annualized treated bleeding rate, decreasing from 21.2 to 4.61. Sutacimig showed a favorable safety profile, with most adverse events (AEs) being mild to moderate in severity, and no reported thromboses or discontinuations due to AEs.

HMB-002 – a new investigational subcutaneous therapy for von Willebrand disease. HMB-002 is a new investigational subcutaneous therapy for patients with von Willebrand disease (VWD) not currently approved by the FDA. It is a bioengineered antibody designed to increase levels of both von Willebrand factor (VWF) and factor VIII by prolonging the survival of VWF in the body. HMB-002 is designed as a prophylactic therapy to prevent bleeding in people will all types of VWD.

Hemab Therapeutics presented their data at the ISTH meeting in June of this year and is based on a pioneer trial program designed to evaluate the safety, tolerability, pharmacokinetics, and efficacy of HMB-002 in individuals with VWD. The study demonstrated that an initial single subcutaneous dose of HMB-002 resulted in consistent and sustained increases in VWF and factor VIII levels. Within 14 days, mean VWF rose >1.5-fold from the baseline reading. A clinical trial in patients is ongoing.

RECENTLY FDA-APPROVED REBALANCING AGENTS

Three new treatment products recently FDA approved for hemophilia which work by rebalancing the clotting system are designed to help blood clot better by adjusting the body's natural clotting balance – the balance between the natural blood clotting proteins and the natural blood anticoagulant (blood "thinning") proteins. In hemophilia, the decreased levels of clotting factor levels result in tipping this balance toward excessive bleeding. To rebalance the clotting system, newer drugs are being developed to lower the natural anticoagulant proteins. Two of these newer drugs block something called tissue factor pathway inhibitor (TFPI), a natural anticoagulant. These are concizumab (Alhemo) and marstacimab (Hympavzi). Another novel drug called fitusiran (Qfitlia) is a bioengineered small interfering RNA molecule which lowers antithrombin levels (another anticoagulant protein).

Alhemo (concizumab) - Approved by the FDA as a once-daily subcutaneous prophylactic treatment to prevent bleeding in Hemophilia A or B without inhibitors. NovoNordisk announced in July this year that the FDA approved Alhemo (concizumab) injection as a once daily prophylaxis to prevent bleeding in adult and pediatric patients 12 years and older with hemophilia A or B without inhibitors, expanding on its prior December 2024 approval for hemophilia patients with inhibitors. With approval, Alhemo offers a subcutaneous injection treatment option for these hemophilia patients.Alhemo is designed to block a protein called tissue factor pathway inhibitor (TFPI) which is a normal blood factor that prevents blood from clotting. By blocking TFPI, Alhemo helps "rebalance" the clotting system is persons with hemophilia A or B. In the phase 3 Explorer8 Trial there was a reduction in annualized bleeding rate of 79% for hemophilia B patients and 86% for hemophilia A patients.

Qfitlia (fitusiran) - Approved by the FDA for prophylaxis in patients with hemophilia A or B with or without inhibitors. In March of this year the FDA approved Sanofi's Qfitlia (fitusiran), the first antithrombin-lowering therapy for prophylaxis to prevent or reduce bleeding episodes in adult and pediatric patients (aged 12 or older) with hemophilia A or B with or without inhibitors.Qfitlia acts by "rebalancing" the blood clotting system by lowering antithrombin levels, a protein that inhibits blood clotting. Qfitlia helps restore clotting balance in people with hemophilia. Qfitlia uses small-interfering RNA technology, which enables low treatment frequency, subcutaneous dosing, and low volume injections. Subcutaneous injections offer consistent protection with as few as six injections a year with a prefilled pen.The approval of Qfitlia by the FDA is based on data from the ATLAS phase 3 studies that demonstrated significant bleed reduction of 71% in the annualized bleeding rate for patients without inhibitors treated with Qfitlia prophylaxis compared to clotting factor concentrate on-demand. The study ATLAS-KIDS is in progress for children under 12 years.

With Qfitlia, there is the potential for significant adverse reactions, including thrombotic events as a result of the lowered antithrombin levels. However, recommendations for reduced doses of clotting factor used for managing breakthrough bleeding and antithrombin-guided dosing strategy to optimize the risk-benefit ratio should lessen the risk of thrombotic events.

Hympavzi (marstacimab) – FDA-approved. In October 2024 Pfizer's Hympavzi was FDA-approved for the treatment of hemophilia A and B without inhibitors for persons with hemophilia 12 years of age and older. It is given once weekly in a single-use pen . Trials are underway for children under 12 and those with an inhibitor. Hympavzi is designed to bind and block the activity of tissue factor pathway inhibitor (TFPI) rebalancing the clotting system, similarly to Alhemo. Hympavzi's approval was based on positive data from BASIS, an ongoing Phase 3 clinical study that assessed the safety and efficacy in hemophilia A or B with or without inhibitors ages 12 years to adults.

Hemab Therapeutics presented their data at the ISTH meeting in June of this year and is based on a pioneer trial program designed to evaluate the safety, tolerability, pharmacokinetics, and efficacy of HMB-002 in individuals with VWD. The study demonstrated that an initial single subcutaneous dose of HMB-002 resulted in consistent and sustained increases in VWF and factor VIII levels. Within 14 days, mean VWF rose >1.5-fold from the baseline reading. A clinical trial in patients is ongoing.

Unite for Bleeding Disorders

Eight is GREAT! 2025 Walk a huge success.

On August 16th more than 200 people came together at Mt. Echo Park to celebrate 8 years of Unite Walks – and once again we couldn't have asked for better weather!!

The Unite for Bleeding Disorders Walks would not have been possible without the extremely generous support of all of you and our National & Local Sponsors. Our National Presenting Partners: Takeda & the Hemophilia Alliance, National Community Partner: Sanofi, National Virtual Partners: Genentech and our Local Sponsors: Novo Nordisk, Dave Long and the Daniels Family. THANK YOU!

The following awards were given out during the Walk ceremony. These numbers are based on registered participants and donations as of Friday evening at 10pm.

First, we would like to announce our Factor Club Members. Medals were given to people who raised at least $500 this year. In alphabetical order:

Les Gunzehnauser
Kelsey Johnson
Lindsey Long
Lindsay and Michael Schulte

Our top 3 teams by way of registered participants who raised an average of $25 per person are:

3rd place with 17 walkers, Courageous Keene Kids
2nd place with 21walkers, Team HTC – Cincinnati Childrens' HTC
1st place team with 37 walkers, is The Mav Pack

Our top 3 individual fundraisers are:

3rd place with $1,805 raised, Lindsey Long
2nd place with $2,582 raised, Kelsey Johnson
1st place individual with $3,000 raised, is Lindsay Schulte

Our top 3 team fundraisers are:

3rd place with $1,805 raised, Team Lions, Tigers & Bears
2nd place with $2,582 raised, The Mav Pack
1st place, with $3,050 raised, Triad Manufacturing

Please save the date for August 22, 2026 at Mt Echo Park

To date we have raised just under $29,000. Donations can still be made until December 31, 2025 if you would like to contribute.

Over these 8 years we have raised more than $130,000 for our local programs and services.....and could not have done it without you.

Donor Thank You

We would like to thank everyone that has contributed to Tri-State Bleeding Disorder Foundation (TSBDF). You have helped to make TSBDF a source of education and support for the bleeding disorder community. This page is only a small token of our appreciation for everyone's contributions, whether they are financial, in kind, or other. We truly appreciate all that you have given!

FOUNDATION CONTRIBUTORS

$30.000 and up

Cascade Hemophilia Consortium

$5,000

Charles and Ruth Seligman Foundation

Elsa M Heisel Sule Charitable Foundation

$1,000

Colburn-Keenan Foundation

PhRMA

ORGANIZATIONAL CONTRIBUTORS

$30,000-$40,000

Novo Nordisk

Sanofi

$10,000-$10,999

CCHMC HTC

Takeda

$5,000-$9,999

Accredo SP

CSL Behring

Genentech USA

Infucare RX

Pfizer

$1,500-$4,999

Bayer Healthcare

Drugco SP

HEMA Biologics

Optum Rx

Soleo Health

TRI-STATE Bleeding Disorder FOUNDATION

Thank You

Donations listed are from 1/1/25-11/25/25/

INDIVIDUAL CONTRIBUTORS

$5,000-$5,999
Scott Crawley
Paul and Beth Mattingly

$2,000-$2,999
Scott Crawley
Kathryn French
Lindsay and Mike Schulte
Triad Manufacturing

$1,000-$1,999
Stoermer Anderson
Elizabeth Billow
Columbus Equipment Company
Jack and Madeline Heffner
Lindsey and David Long
LA Raterman and Associates

$500-$999
Duane Bellamy
Denis Barry, Sr.
Drew Barry
Tony Barry
Randolph Freking
Dr. Ralph and Barbara Gruppo
Dr. Les & Cheryl Gunzenhaeuser
Kelsey Johnson
Thomas Kerpics
Thomas Kropfeld
Anthony and Roberta Michel
Keith and Victoria Peterson
Haibo Wang

$200-$499
Peter Abner
Jenifer Berger
Jack Campbell
Amanda Criscione
Scott and Jennifer Daniels
James Erb
Dr. Erin Espinoza
Susan Fine
David Fish
Donnie Johnson
L & L Jones
Sue Jones
Lisa Littner
Michelle Mattingly
Dr. Robert Means
Tony and Krystle Monnin
Ivy & Royan Morris
Dr. Joseph and Mary Palascak
June Tebbe
Leonard and Christine Traficanti
Van Vieregge
Tiffany and Mike Weigle
Lisa White
Ashlee Wolf

$100-$199
Diane Appleberry
Joseph and Cathy Augustine
Jeff Blau
Robbin Blau
Karl Boppel
Audra Buckley
Mary Casteel
Amanda Criscione
Nickie Curry
Teresa DAurizio
Glenn Gollobin
Sarah Gross
Jacob Gunzenhaeuser
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Greg Isaac
Wanda Johnson
Reed Johnston
Marcy Klemenz
Larry Kohn
Jeana Kropfeld
Helen Lamping
Michelle Lemker
Gina Meyers
Carol Monnin
Matthew Montemurro
Susan Neumann
Mary Partin
Tom Welch and Polly Partin-Welch
Amber Preston
Andy and Ruth Proeschel
Wendy Puccini
Lisa Raterman
Steve and Brenda Rebsch
Mike and Susan Richardson
Rania Salem
Debra Schankweiler
Larry and Alice Shade
Patricia Simoni
Kelly Smith
Dr. Cristina Tarango
Gary Topper
Kimberly Tuerpe
Norbert Weidner
Lori Weigel
Mark Witte
Ava Wright
Kevin Yaeger
Lynn Yaeger
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Cady Artmayer
Tina Asco'ugh
Kathryn Asher
Carolyn Atwood
Marjorie Bailey
Aimee Baston
Pati Besl
Holley Blagdon
Michele Bunke
Carolyn Burke
Erica Capps
Susan Council
Jennifer Crosby
Joselle Cuckler
Claire Dotson
Julie Doyle
Allison Early
Diana Ediskey
Alison Ficklin
Patti Fields
Mischelle Figgins
Bethany Finn
Janis Fisher
Gail Goedde-Chin
Julie Hahn
Connie Harpring
Courtney Hassebrock
Alexandra Hoffman
Dale Irwin
Megan Jackson
Cynthia Jennings
GE Kauscher
Jeff and Kacey Kersting
Olivia Lauer
Ellen and Jim Mahlenkamp
Jack Marshall
Molly Mays
Marianne McCabe
Lyndsay McCullers
Marie Meyers
Andrew Monnin
Dr. Eric Mullins
Perry and Debbie Nardelli
Kathleen Neff
Patti O'Dell
Beth Pantazi
Beverly Pawsat
Kelsey Perrin
Stacey and Thomas Peters
Heather Richards
Sherry Ritzenthaler
Sherry Roark
Regina Sanders
James Sellers
Bridget Sherman
Ellie Smith
Teresa Spahn
Laura Steel
Zoe Stovik
Janet Sudbrack
Patrick Taylor
Mary Thatcher
Shawn Thomas
Tyler Tillman
David Vance
Jamesa VanVelzel
Clark Vaughan
Thomas Watkins
Debbie Welte
Mary Williams
Amy Williams
Ann Yaeger

TSBDF Scholarships

BY RALPH GRUPPO, M.D.

There were a total of 11 scholarship applicants for both scholarships. Six individuals applied for the Gina Stack Scholarship with plans to enter a health-related field. Ten individuals applied for the TD Hughes Scholarship including 5 new applicants and five applicants who also applied for the Gina Stack Scholarship. $10,000 was allocated by the TSBDF Board for scholarships. Lisa Littner, Jeff Kersting, and Ralph Gruppo were on the scholarship committee and scored the applicants based on five criteria: Academic quality; Humanistic quality (such as extracurricular activities, sports, volunteer activities); Overall quality (including potential for chosen career, sincerity of commitment to career of choice, strength of reference letter); Applicant's statement (including feasibility of the goal, anticipation of limitations, sincerity, written by the applicant), and Discretionary (including financial need, special circumstances).

The recipients and awards are listed below:
Gina Stack Scholarship:
1st - Lilly Frye, $2,500. Lilly is a first-year applicant with mild hemophilia A. She is attending Bellarmine University as a Freshman in the BS program in Biology. Her goal is to be a physical therapist.

2nd - Roman White, $1,500. Roman is a first-year applicant with mild hemophilia A. His goal is to be a surgeon. He is a freshman entering the pre-med program at Ohio State University.

3rd - Joey Monk- $1,000. Joey is a first-year applicant whose mother has Type 2 VWD. His goal is to be a physical therapist. He is a freshman in pre-physical therapy at the Bradford satellite campus of the University of Pittsburgh.

TD Hughes Scholarship:
1st- Margo D'Agostino, $2,000. Margo is a second-year scholarship applicant with Type 1 VWD. Margo is in her second year of graduate school at the University of Wisconsin Law School.

2nd- Jonah Ficklin, $1,000. Jonah is a first-year applicant with mild hemophilia A. His goal is to work in computer science. He is a Freshman at the University of Cincinnati in computer science.

3rd- Emily Wolf, $1,000. Emily is a second-year scholarship applicant with Hereditary Hemorrhagic Telangiectasis (HHT). Emily is in her Junior year at the University of Kentucky where she is majoring in Marketing.

4th- Jessica Mains, $1,000. Jessica is a first-year applicant with VWD. Her goal is to obtain an associate degree in Early Childhood Education. She is a Freshman at Maysville Community & Technical College.

This year, with a total of 11 applicants, all of whom were excellent, the decisions were particularly difficult. The scholarship committee wanted to thank the TSBDF Board for their generous allocation of $10,000 for these two competitive scholarships.

Jonah Ficklin was also the recipient of the Peter Ruehlman Scholarship offered through the University of Cincinnati. Jonah will receive a $5,000 scholarship each year for four years thanks to the generosity of Peter and Debra Ruehlman.

Jonah Ficklin

My plans for furthering my education are to stick with UC's computer science program throughout college, and pursue co-ops and internships through it to gain experience in the field. I'm just starting my first year here, and I'm looking forward to the future. A life long love for technology and learning has led me down this path, and having a background with technology, and close friends and family encouraging me to succeed in life has led me to aim high by attending college and hoping to achieve the goal of a successful career in the field of computer science.
Unlike most, I wasn't diagnosed with Hemophilia until I was 15 years old and in my sophomore year of high school. I experienced a joint bleed in my knee when I was 14, I wasn't diagnosed yet, so I had no factor to help treat it. I missed out on the last few weeks of my freshman year of marching band. The fallout of this event eventually led to the diagnosis of me and my brothers, but in the meantime we were confused. Often I was a little more aware I was more prone to injury, but I didn't let that stop me. I continued to do marching band throughout high school, and even got into rock climbing this past year. I also had more apparent mental conflicts with telling myself I was different because of this diagnosis.

Jonah Ficklin

Margo D'Agostino

I am now a second year law student at the University of Wisconsin and an intern with Wisconsin Legislative Council, where I assist in legal research for legislators, staff public hearings on a variety of topics, and help facilitate effective lawmaking. Within the law school, I am an associate on the Wisconsin Law Review (the school's flagship legal journal), a competitor with the moot court team, and treasurer of the Government Law Society. I also am a member of our Health Law Students Association and Public Interest Law Foundation.

Margo D'Agostino

Emily Wolf

Emily Wolf

Currently, I am working on a project with UK medical school where I can educate students about my rare bleeding disorder, HHT. My goal is to spread awareness as many people are unaware of HHT and help others have an easier journey to diagnosis than I did.

One of the biggest challenges being a college student is attempting to manage my symptoms while having a social life and keeping up with school. My migraines and nosebleeds are often unpredictable, and it can be frustrating that I can't live a normal life like my friends can.

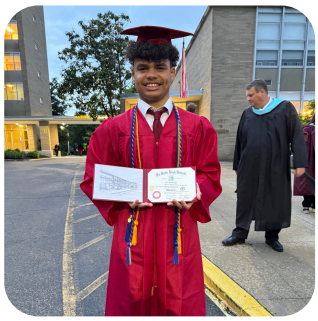
One of the biggest positive aspects of having a bleeding disorder is the fact that I now appreciate life and the times I feel well much more than I used to. I have learned that time is short and I want to make the most of every minute I have on this Earth, which has turned me into a much more positive person.

Roman White

Having a bleeding disorder has taught me how to balance academics with health challenges. I've had to plan ahead, communicate with teachers, and stay disciplined when I miss school for treatments or medical appointments. It has strengthened my determination and helped me develop time management and self-advocacy skills that I now use in both school and work.

One of the biggest challenges has been learning to manage physical limitations, especially when I wanted to participate in sports or other activities. There have been times when I've had to sit out or take extra precautions, which can be frustrating. However, it's also taught me patience, responsibility, and how to stay positive in difficult situations.

A major positive has been the strong sense of community and purpose it's given me. I've met incredible people through the bleeding disorder community, and it's motivated me to use my voice to advocate for others. It's also shaped my career interests and helped me appreciate how far medical care has come, and how I can be part of continuing that progress.



Roman White

Lilly Frye

Lilly Frye

Having a bleeding disorder has brought me many challenges along my educational journey, but it was also what brought me to think about pursuing a career in physical therapy. The events I experienced through my bleeding disorder shaped me and brought to my attention where I want to be so that I can help people in a way that may be familiar to me.

With my bleeding disorder I experience hypermobility which brought issues with my joints. I am a dancer, and I experience constant chronic pain and I have had several injuries or bleeds during my career. This set me back several times, but with support from my family, friends, teachers, and healthcare team I was able to get back to doing what I love.

Having a bleeding disorder may sometimes make me more cautious in what I do, but it has also brought a new perspective on things. Learning more about bleeding disorders has been the best thing for me. I can learn more about my personal case and apply it to life in general. My bleeding disorder in a way was what brought me to my current chosen degree pathway.

TSBDF Events

The Tee(SBDF) Up Golf Clinic

The first Tee Up Golf Clinic took place Tuesday, June 10th-13th at the Tri County Golf Ranch. The program was for bleeding disorder patients and their siblings, ages 8-17 and included Pro instruction, golf clubs, lunch, snacks, and drinks. Each participant also received a camp t shirt and golf shirt.

The Golf Pro, along with NKU student athletes, worked with our participants on all skills including chipping, putting, driving and golf course etiquette. Fun, skill building games were played each day including putting and driving contests. Shawn Thomas from CCHMC HTC led a short session about safe sports during lunch on Wednesday.

We ended Friday with an awards ceremony where each participant received an award for a skill they improved during the week. Our golfers were able to take home their new set of clubs to work on their golf game over the summer and were even given gift cards to come back to the Tri-County Golf Ranch for 2 free buckets of balls on the driving range.

This program was made possible by a grant from the Elsa Sule Foundation.

The Tee Up Golf Reunion and Club Turn In

Our golfers reunited on Sunday, October 5th for our Golf Clinic reunion and to turn in their clubs for the season. Attendees enjoyed lunch and then we headed to the driving range to practice our swings. The golfers all turned in their clubs before they left. They will receive their same clubs back next year or receive a new set if they've grown. We can't wait to see everyone next year!

TSBDF Family Education Day at King's Island

It was a great day for the TSBDF Family Education Day at King's Island on Saturday, June 17th! Our families enjoyed lunch, visiting with our sponsors, and then learning about important advocacy issues that are affecting our community from Randi Clites. Thank you to our sponsors: Sanofi, Novo Nordisk, Accredo, CCHMC HTC, Infucare, and Drugco for their support!

TSBDF Fishing Clinic

TSBDF Family Fishing Clinic took place on Saturday, September 20th at Lake Isabella

We started our day with lunch and a ice breaker game. James, the Naturalist, gave everyone a quick lesson on the fish we would be catching and the bait used to fish.

It was a fun day for all, and we look forward to hosting this program again in 2026!

TSBDF Ask the Doc/Annual Meeting

The TSBDF Ask the Doc/Annual Meeting took place on Wednesday, November 5th at The Graduate Hotel.There were over 80 patients/family members who attended the event.

Dr. Maria Carter-Febres from CCHMC HTC, Dr. Kristine Karkoska from UC's HTC, and Dr. Erin Espinoza from Tri-Health Hematology made up our panel for this event. All three physicians took the time to talk about current therapies and research, updates at all of the centers and then took questions from the audience.

We want to thank our sponsors who helped make this event possible:
Gold level: Pfizer and Novo Nordisk
Silver Level: Genentech and Sanofi
Accredo SP, Bayer, Cincinnati Children's Hospital HTC,
HEMA Biologics, Infucare, Optum, Soleo Health, & Takeda

Annual Meeting (Continued)

Alternative Funding Plans

BY LISA LITTNER

Our last Blood Ties edition focused on tips for understanding your insurance, including a look at patient assistance programs, copay maximizers, and copay accumulator programs. In this edition, we will focus on alternative funding plans (AFPs). In recent years, new cost-containment strategies have emerged in the health insurance landscape, particularly targeting high-cost specialty medications. One such approach, known as an AFP, has drawn attention for its complex and concerning impact on patients who rely on costly, life-sustaining treatments. Understanding how these programs operate and the potential risks they pose is important for people with a bleeding disorder and their families.

Alternative Funding Plans are for-profit, third-party vendors that work with self-funded health insurance plans. They are not insurance companies or pharmacy benefit managers. AFPs target high-cost specialty drugs, such as bleeding disorders medications. AFPs invite health insurance companies to drop coverage for high-cost specialty drugs as part of their sales pitch. Dropping this coverage makes the beneficiary (the person with a bleeding disorder) uninsured for those drugs.

In some cases, prior authorizations for specialty drugs are denied when an AFP is in place. When this happens, the AFP will try to obtain the person's bleeding disorder medication through the manufacturer's patient assistance program. However, these patient assistance programs were created to help truly uninsured people, so the person with a bleeding disorder does not technically meet these requirements to qualify. When this happens, the AFP may try to obtain medication from a foreign country or seek assistance from a charity organization.

AFPs may provide employers with short-term cost savings, but they can delay treatment and increase costs for the person with a bleeding disorder and the healthcare system. People with bleeding disorders may be surprised to learn that they have an AFP. At times, they will not know until their treatment center team receives a request to change their prescription.

Visit the All Copays Count Coalition's website to learn about legislative action at the state and federal levels against copayment accumulators and learn how you can get involved.

If you or your family member has experienced an AFP, copayment maximizer, or copayment adjuster, contact your treatment center. With your permission, they can contact regional or national organizations that can help you with advocating.

Alhemo®
concizumab-mtci
injection | 60 mg | 150 mg | 300 mg pens

More than a pen—

YOUR EVERYDAY BLEED PROTECTION[a]

Prophylaxis treatment in a prefilled, subcutaneous pen to prevent or reduce the frequency of bleeding episodes in adults and children 12 years of age and older with hemophilia B with or without inhibitors or hemophilia A with or without inhibitors. It is not known if Alhemo® is safe and effective in people receiving ongoing immune tolerance induction or in children younger than 12 years of age

[a]It is important to follow the daily dosing schedule of Alhemo® to stay protected against bleeding.

Royal lives with hemophilia B with inhibitors, uses Alhemo®, and is an employee of Novo Nordisk.

NO IV infusions

NO mixing

NO vials

NO refrigeration required[b] (up to 4 weeks after first use)

Needles provided separately and may require a prescription in some states.
[b]Store in refrigerator before first use. After first use, Alhemo® can be stored at room temperature below 86 °F (30 °C) or in a refrigerator at 36 °F to 46 °F (2 °C to 8 °C) for up to 4 weeks.
IV=intravenous.

Important Safety Information

What is the most important information I should know about Alhemo®?

- **It is important to follow the daily dosing schedule of Alhemo® to stay protected against bleeding.** This is especially important during the first 4 weeks of treatment to make sure a correct maintenance dose is established. Use Alhemo® exactly as prescribed by your healthcare provider (HCP). **Do not** stop using Alhemo® without talking to your HCP. If you miss doses or stop using Alhemo®, you may no longer be protected against bleeding
- **Your HCP may prescribe factor VIII, factor IX, or bypassing agents during treatment with Alhemo®.** Carefully follow your HCP's instructions regarding when to use on-demand factor VIII, factor IX, or bypassing agents and the recommended dose and schedule for breakthrough bleeds

Do not use Alhemo® if you are allergic to concizumab-mtci or any of the ingredients in Alhemo®.

Before using Alhemo®, tell your HCP about all of your medical conditions, including if you:

- Have a planned surgery. Talk to your HCP about when to stop using Alhemo® and when to start it again if you have a planned surgery
- Are pregnant, breastfeeding, or plan to become pregnant or breastfeed. It is not known if Alhemo® may harm your unborn baby or if Alhemo® passes into your breast milk
  - Your HCP may do a pregnancy test before you start treatment with Alhemo®
  - **Females who are able to become pregnant**, talk to your HCP about using effective birth control (contraception) methods during treatment with Alhemo® and for 7 weeks after ending treatment

Tell your HCP about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and supplements.

What are the possible side effects of Alhemo®?

Alhemo® may cause serious side effects, including:

- **Blood clots (thromboembolic events).** Alhemo® may cause blood clots to form in blood vessels, such as in your arms, legs, heart, lung, brain, eyes, kidneys, or stomach. You may be at risk for getting blood clots if you use high or frequent doses of factor products or bypassing agents to treat breakthrough bleeds, or if you have certain conditions. Get medical help right away if you have any signs and symptoms of blood clots, including: swelling, warmth, pain, or redness of the skin; headache; trouble speaking or moving; eye pain or swelling; sudden pain in your stomach or lower back area; feeling short of breath or severe chest pain; confusion; numbness in your face; and problems with your vision
- **Allergic reactions.** Alhemo® can cause allergic reactions, including redness of the skin, rash, hives, itching, and stomach-area (abdominal) pain. Stop using Alhemo® and get emergency medical help right away if you develop any signs or symptoms of a severe allergic reaction, including: itching on large areas of skin; trouble swallowing; wheezing; pale and cold skin; dizziness due to low blood pressure; redness or swelling of lips, tongue, face, or hands; shortness of breath; tightness of the chest; and fast heartbeat

The most common side effects of Alhemo® include: bruising, redness, bleeding, itching, rash or lump at the injection site, headache, and hives. These are not all the possible side effects of Alhemo®. Call your doctor for medical advice about side effects.

Please see Brief Summary of information about Alhemo® on the following page.

Ready to discover more?
Ask your doctor about Alhemo® or visit **Alhemo.com** by scanning the QR Code

Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.

Alhemo®
concizumab-mtci
injection | 60 mg | 150 mg | 300 mg pens

Brief Summary of information about Alhemo® (concizumab-mcti) injection

Rx Only

This information is not comprehensive.
- Talk to your healthcare provider or pharmacist
- Visit www.novo-pi.com/alhemo.pdf to obtain FDA-approved product labeling
- Call 1-888-668-6732

What is the most important information I should know about Alhemo®?

- **It is important to follow the daily dosing schedule of Alhemo® to stay protected against bleeding.** This is especially important during the first 4 weeks of treatment to make sure a correct maintenance dose is established. Use Alhemo® exactly as prescribed by your healthcare provider. **Do not** stop using Alhemo® without talking to your healthcare provider. If you miss doses, or stop using Alhemo®, you may no longer be protected against bleeding.
- **Your healthcare provider may prescribe factor VIII, factor IX or bypassing agents during treatment with Alhemo®.** Carefully follow your healthcare provider's instructions regarding when to use on-demand factor VIII, factor IX or bypassing agents, and the recommended dose and schedule for breakthrough bleeds.

See **"How should I use Alhemo®?"** for more information on how to use Alhemo®.

What is Alhemo®?

Alhemo® is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children 12 years of age and older with:
- hemophilia A with or without factor VIII inhibitors
- hemophilia B with or without factor IX inhibitors

It is not known if Alhemo® is safe and effective in people while receiving ongoing Immune Tolerance Induction (ITI).

It is not known if Alhemo® is safe and effective for hemophilia A and B with and without inhibitors in children younger than 12 years of age.

Do not use Alhemo® if you are allergic to concizumab-mtci or any of the ingredients in Alhemo®.

Before using Alhemo®, tell your healthcare provider about all of your medical conditions, including if you:

- have a planned surgery. Your healthcare provider may stop treatment with Alhemo® before your surgery. Talk to your healthcare provider about when to stop using Alhemo® and when to start it again if you have a planned surgery.
- are pregnant or plan to become pregnant. It is not known if Alhemo® may harm your unborn baby. **Females who are able to become pregnant:**
  - Your healthcare provider may do a pregnancy test before you start treatment with Alhemo®.
  - You should use an effective birth control (contraception) during treatment with Alhemo® and for 7 weeks after ending treatment. Talk to your healthcare provider about birth control methods that you can use during this time.
- are breastfeeding or plan to breastfeed. It is not known if Alhemo® passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby during treatment with Alhemo®.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Know the medicines you take. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How should I use Alhemo®?

- Use Alhemo® exactly as prescribed by your healthcare provider.
- Your healthcare provider will provide instructions for stopping (discontinuing) your current treatment when switching to Alhemo®.
- Inject Alhemo® 1 time a day.
- **Your healthcare provider should show you or your caregiver how to use Alhemo® before you use it for the first time.**
- Alhemo® is given as an injection under the skin (subcutaneous injection) by you or a caregiver.
- Ask your healthcare provider if you need to use a different injection technique. For example, children and people who are lean may need to inject into a pinched fold of skin to avoid injecting too deep (into the muscle).
- Change (rotate) your injection site with each injection. **Do not** use the same site for each injection.
- You will inject a larger dose (a loading dose) of Alhemo® on your first day of treatment. Then your healthcare provider will prescribe a dose to inject 1 time a day until your maintenance dose is established.
- To determine the right maintenance dose for you, your healthcare provider will do a blood test to check the amount of Alhemo® in your blood. Your healthcare provider may do additional blood tests during treatment with Alhemo®.

How should I use Alhemo®? (cont'd)

- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- Your healthcare provider will provide information on the treatment of breakthrough bleeding during your treatment with Alhemo®.
- Do not share your Alhemo® pens and needles with another person, even if the needle has been changed. You may give another person an infection or get an infection from them.
- **If you miss a dose of Alhemo® during the first 4 weeks of treatment,** contact your healthcare provider right away. Your healthcare provider will tell you how much Alhemo® to inject.
- **If you miss a dose of Alhemo® after your daily maintenance dose is established:**
  - For 1 missed dose, continue your daily maintenance dose.
  - For 2 to 6 missed doses, give 2 doses as soon as you remember. Then continue your daily maintenance dose the next day.
  - For 7 or more missed doses, contact your healthcare provider right away as you will need to receive a new loading dose before continuing your daily maintenance dose.
  - If you are unsure about how much Alhemo® to inject, contact your healthcare provider.

What are the possible side effects of Alhemo®?

Alhemo® may cause serious side effects, including:

- **Blood clots (thromboembolic events).** Alhemo® may cause blood clots to form in blood vessels, such as in your arms, legs, heart, lung, brain, eyes, kidneys, or stomach. You may be at risk for getting blood clots during treatment with Alhemo® if you use high or frequent doses of factor products or bypassing agents to treat breakthrough bleeds, or if you have certain conditions. Get medical help right away if you have any signs and symptoms of blood clots, including:
  - swelling, warmth, pain, or redness of the skin
  - headache
  - trouble speaking or moving
  - eye pain or swelling
  - sudden pain in your stomach or lower back area
  - feeling short of breath or severe chest pain
  - confusion
  - numbness in your face
  - problems with your vision
- **Allergic reactions.** Alhemo® can cause allergic reactions, including reactions that can be serious. Stop using Alhemo® and tell your healthcare provider right away if you have redness of the skin, rash, hives, itching, and stomach-area (abdominal) pain. Stop using Alhemo® and get emergency medical help right away if you develop any signs or symptoms of a severe allergic reaction, including:
  - itching on large areas of skin
  - trouble swallowing
  - wheezing
  - pale and cold skin
  - dizziness due to low blood pressure
  - redness or swelling of lips, tongue, face, or hands
  - shortness of breath
  - tightness of the chest
  - fast heartbeat

The most common side effects of Alhemo® include:
- bruising, redness, bleeding, itching, rash, or lump at the injection site
- headache
- hives

These are not all the possible side effects of Alhemo®.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store Alhemo®?

- **Before first use:**
  - Store unused Alhemo® pens in the refrigerator between 36°F to 46°F (2°C to 8°C).
- **After first use:**
  - Store the Alhemo® pen in the refrigerator between 36°F to 46°F (2° C to 8°C) or at room temperature below 86°F (30°C) for up to 28 days.
  - Write the date of first use in the space provided on the carton.
  - Throw away (discard) the Alhemo® pen 28 days after first opening even if some medicine is left in the pen.
- Store Alhemo® with the cap on and keep it in the original carton to protect from light.
- Do not store Alhemo® in direct sunlight and keep away from direct heat.
- When stored in the refrigerator, do not store the pen directly next to the cooling element (the part that cools the refrigerator).
- Do not freeze Alhemo®.
- Do not use Alhemo® if it has been frozen or if it has been stored above 86°F (30°C).

Keep Alhemo® and all medicine out of the reach of children.

More detailed information is available upon request.

Available by prescription only.

For information contact: Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536, USA, 1-888-668-6444

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At: Novo Nordisk A/S, Novo Allé 1, 2880 Bagsværd, Denmark

novo nordisk®

ALTUVIIIO™
Antihemophilic Factor (Recombinant),
Fc-VWF-XTEN Fusion Protein-ehtl

Looking for information? Your CoRe can help!

Connect with
Laith Elkurd
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857-270-1962

Learn more at ALTUVIIIO.com by scanning the QR code

ALTUVIIIO™
Antihemophilic Factor (Recombinant),
Fc-VWF-XTEN Fusion Protein-ehtl

sanofi

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*

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CALENDAR OF EVENTS

January 17th
OBDC Ohio Ambassador Training

February 21st or 22nd
Family Education Conference @ Great Wolf Lodge

March 4th-6th
NBDF Washington Days

March 25th
Ohio Statehouse Day

May 3rd
Flying Pig Marathon

May TBD
TSBDF Search for the Holy Grail Scavenger Hunt

June TBD
Tee(SBDF) Up Kids Golf Clinic

June 20th
Family Education Day @King's Island

July 5th-17th
Camp NJoyItAll

July 30th-Aug 2nd
FamOhio

August 22nd
Unite Walk at Mt. Echo Park

August 13th-15th
NBDF Bleeding Disorder Conference

November TBD
Ask the Doc/Annual Meeting

Follow us on Facebook & visit our website at www.TSBDF.com to be the first to receive Chapter updates & program announcements!