





New Executive Board Members Upcoming Events Registration Opportunities Fundraisers Bleeding Disorder Education 4th Quarter Highlights



**WINTER 2025** 

The



**BLOODLINE** NEWSLETTER

PROUD MEMBERS OF THE HEMOPHILIA FEDERATION OF AMERICA AND THE NATIONAL BLEEDING DISORDERS FOUNDATION

### **BDH Staff**

#### **EXECUTIVE DIRECTOR**

Brooke Loving bdh\_director@bdheartland.org



### ADMINISTRATIVE & PROGRAMS ASSISTANT

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(MEMBERS AT LARGE) Nate Stirgus Asa Kelley Dayna Leichty Nicholas Reuter Orion Wilkerson Devin Smith

### **Board of Advisors**

Mya Anderson Becca Markl Executive Director's Letter (Brooke Loving)

### **BDH 2025 Executive Board Introductions**

### **Recap of 4th Quarter Events**

Buff City Soap
 Board Retreat

**Educational Bleeding Disorder Articles** 

2025 BDC for NBDF & HFA Symposium

### Advocacy Day

### **Upcoming Annual Events**

- Annual Meeting March. 14-16
- Golf Event June 2
- Summer Camp June 15-20
- Men's Event July 11-13
- Family Education Day July 26
- Adult Retreat Aug. 16-17
- Walk for a Cause Sept. 27

### **CONTACT INFORMATION**



Bleeding Disorders of the Heartland 103 5th Ave Durant, Iowa 52747

Tel: (319) 721-1664

Email us at: bdh\_director@bdheartland.org

The Bloodline is a publication of the Bleeding Disorders of the Heartland. The Bleeding Disorders of the Heartland is a voluntary education and advocacy organization which neither recommends nor endorses the products and services noted within this publication and does not make recommendations concerning treatment regimes for individuals. BDH suggests that you consult your physician or local treatment center before pursuing any course of treatment. The Bloodline is published four (4) times a year.

To: Our Bleeding Disorders of the Heartland Family



BDH 103 5th Ave Durant, Iowa 52747

### Contact Brooke by email at:

bdh\_director@bdheartland.org

### A Letter from BDH Executive Director, Brooke Loving

### Dear BDH Family,

As we step into 2025, I want to take a moment to reflect on the incredible contributions each of you have made to our community over the past year. Your dedication, support, and advocacy have helped us make great strides in raising awareness and improving the lives of those affected by bleeding disorders.

•••

Looking ahead, we are excited about the many opportunities and events coming up in 2025. From educational programs to advocacy efforts at the state and federal level, there will be countless ways for you to get involved, learn, and grow with us. We encourage you to join us in these initiatives and make an even greater impact in the year ahead.

We are truly grateful for your continued involvement, and we invite you to consider becoming even more engaged in 2025 and beyond. Together, we can create positive change and provide the support needed for individuals and families affected with bleeding disorders.

Thank you for being a vital part of our community. We look forward to all that we will achieve together in the year ahead.

Blessings, Brooke Loving Executive Director

HAPPY Valentine's Day **Bleeding Disorders** of the Heartland **Board of Directors & Staff** is Wishing you a day bursting with love, giggles, and unforgettable shenanigans with your favorite people who make your heart do a happy dance! www.bdheartland.org



### Connect with an ALTUVIIIO® Peer Mentor

ALTUVIIIO Peer Mentors are real patients or caregivers who have had similar experiences to yours.

### You'll have the opportunity to:

- Ask questions
- Hear firsthand experiences
- Learn helpful tips
- Get to know others in the community

Maybe it's because I've always had such great support, but engaging with others is the best way for me to stay happy.

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AJ ALTUVIIIO patient AJ is a promotional speaker compensated by Sanofi.

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### Sign up today to meet a Peer!



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- Ven

# Events for 2025

### <u>Advocacy Day</u>

FEBRUARY Advocacy training and visiting Iowa Capital 4-5th Des Moines, Iowa

### <u>Annual Meeting</u>

MARCH 14-16th Weekend full of education and connection time! Des Moines, Iowa

### Factoring Fairways Golf Event

JUNE One of our biggest fundraising events! 2nd Pleasant Hill, Iowa

### Bleeding Disorders Camp

JUNE 15-20th Classic summer camp fun with lots of bleeding disorders education! Mount Vernon, Iowa

### Regional Men's Event

JULY New this year! Keep an eye out for more details! 11-13th Location TBD

### Family Education Day

JULY Education & Fun all in 1 event! 26th Waterloo, Iowa

### Adult Retreat

AUGUSTEducational time for adults to connect.16-17thCedar Rapids, Iowa

### <u>Unite Walk</u>

SEPTEMBER 27th Step Right Up and Walk for a Cause! Fundraising event! Hiawatha, Iowa

### FAB - Women's Regional Event

OCTOBER A returning favorite! 10-12 Kansas City, Missouri

For detailed information:

Call Brooke (319)721-1664 or bdh\_director@bdheartland.org

# Meet our 2025 EXECUTIVE COMMITTEE



President Julie McAnally

Julie and her husband have two active boys, both who are affected with Hemophilia. She is also the Director of Growth & Development for Holmes Murphy where she helps develop others to meet their unique potential.



Vice President

#### Meg Gillins

Meg Gillins lives in Cedar Falls with her husband and five active kids. Her son was diagnosed with Moderate Hemophilia A at birth, and her father and one of her daughters are diagnosed with Mild Hemophilia A. Treasurer

### Devin Smith

Devin Smith currently lives in Ankeny, IA and works at John Deere. He is personally affected by severe Type 1 Von Willebrand's Disease. He's looking forward to helping the bleeding disorder community in lowa!



Secretary Orion Wilkerson

Orion is a proud graduate of St. Ambrose University, where he earned degrees in Cyber Security and IT Management. As a seasoned professional, he operates mostly in the cyber security field while also running his own successful IT consulting business.



History thru 1940s

#HFA2025



"We owe it to the previous generations, to ourselves, and to our children to **not forget the past."** 

**Register Now!** 

WWW.HFASYMPOSIUM.ORG

"As a mother to a child with hemophilia, this was a great opportunity to educate about our history. He is still talking about it."



At Symposium we have kids and teens covered!

Camp Symposium & Teen Camp! So you can enjoy all the educational sessions, breakouts, and exhibits at your pace!



# **APPLY TODAY!**

### CONNECTIONS FOR LEARNING GRANT

### AURORA, COLORADO AUGUST 21-23, 2025



NATIONAL BLEEDING DISORDERS FOUNDATION

Have you applied? The Connections for Learning Grant (formerly NBDF Travel Grant) is designed to support those who may need financial assistance to attend the 2025 Bleeding Disorders Conference! Apply by February 24th

<u>Click here to learn more about these travel grants!</u>



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Panda Express ongoing Fundraiser

AEXA





Regular exercise is important. But moods vary. No two days are exactly the same. So we asked celebrity trainer Dolvett Quince to create a series of exercise videos called H-Fit. Each video features a different **hemophilia-friendly workout**. And each workout is built around a different mood. How are you feeling today? H-Fit has got you covered.

Always talk to your health care provider before starting any new exercise routine.



Scan for H-Fit.com

Sign up with Novo Nordisk and register at H-Fit.com to get free access to the H-Fit video library.

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# MEET DARCIE,

In July 2024, the University of Iowa Health Care Stead Family Children's Hospital established the Level 11 Family Advisory Council (L11 FAC). The mission of the group is "to strengthen patient– and family–centered pediatric health care for children receiving treatment in the University of Iowa Dance Marathon Pediatric Cancer and Blood Disorders Center at Iowa Health Care Stead Family Children's Hospital." The council – currently composed of five family advisors, three L11 staff advisors and facilitator Dr. David Dickens – meets quarterly at the hospital or via Zoom. As the mother of a five–year–old with severe hemophilia A, I was asked to join the council as a family advisor.

The L11 FAC has had two meetings so far. The first meeting in August 2024 focused on developing the group's purpose, protocols and procedures. During the second meeting in November 2024, council members discussed holiday gift giving for oncology patients, central line standards and a pilot project that had children with a weak immune system and central line going to the emergency room when a new fever occurred instead of the 11th floor. (Note: This pilot project took place from December 1, 2024 to December 23, 2024 and is no longer in effect.). We will meet again in February and I have asked to have family education for pediatric bleeding disorder patients as a discussion topic.

I am currently the only family advisor representing hematology and I will serve a two-year term. The other four inaugural family advisors represent oncology, though the group may expand membership to include more families and staff after becoming more established. As the sole hematology representative, I want to ensure the pediatric bleeding disorders community is aware of the council's purpose, current initiatives and how to bring issues to our attention. If you have an issue you would like the L11 FAC to discuss, please email L11SFCH-FAC@uiowa.edu. You are also welcome to contact me directly via email at hoendaO1@gmail.com.



Much love,

Darcie Woodruff



DMADEDAIL

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# BUFF CITY SOAP

THANK YOU TO OUR SPONSOR





FOR SPONSORING THIS FUN EVENT IN JANUARY!

States Lang

CEDAR RAPIDS, IOWA

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# 2025 Board Retreat





The conference room buzzed with anticipation and the aroma of coffee as members gathered for the annual board retreat. We focused on strategic planning, and building connections.

Each member contributed unique insights, fostering a rich exchange of ideas.



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The agenda contained discussions on future goals, projects, and positive impact in the bleeding disorders community. The meeting was filled with the energy fueled by a shared commitment to making a meaningful difference in the coming year. Thank you to our Board Members for giving of their time, gifts and talents.



# ADVOCACY DAY





Bleeding Disorders of the Heartland encourages <u>YOU</u> to be a voice for individuals and families affected with bleeding disorders. Advocacy Day is a day we commit to representing our group and work toward making changes for our bleeding disorder community! Watch the website on the advocacy tab for updates throughout 2025 and beyond.

Thank you to our 2025 Event Sponsors

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Biotherapies for Life<sup>™</sup>

**CSL Behring** 





Visit Our Website
www.bdheartland.org



Our Location 103 5th Ave, Durant, Iowa 52747

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# ADVOCACY DAY 2025





**NEWS LINK** You can view a news article by clicking the <u>HERE</u> or watching on our website.

ADVOCACY DAY 2025 WAS AT THE IOWA STATE CAPITOL ON FEBRUARY 5, 2025 IN DES MOINES. WE HAD PASSIONATE MEMBERS OF THE BLEEDING DISORDERS COMMUNITY COME TOGETHER TO RAISE THEIR VOICES IN SUPPORT OF CRITICAL ISSUES. A BILL WITH A FOCUS ON PBM REFORM, WAS PRESENTED BUT IT ALSO INCLUDED COPAY ACCUMULATOR VERBIAGE, WHICH BDH IS IN SUPPORT OF. THE EVENT INCLUDED POWERFUL TESTIMONY ADVOCATING FOR THE NEEDS OF THOSE AFFECTED BY BLEEDING DISORDERS. IT WAS EXCITING TO WITNESS THE BILL'S PROGRESS, AS THE COMMUNITY'S COLLECTIVE EFFORTS HELPED DRIVE IT FORWARD. THE DAY HIGHLIGHTED THE POWER OF UNIFIED ADVOCACY IN CREATING MEANINGFUL CHANGE FOR THE BLEEDING DISORDERS COMMUNITY.

For more information please visit the ADVOCACY tab at <u>www.bdheartland.org</u>

# **MARCH IS**



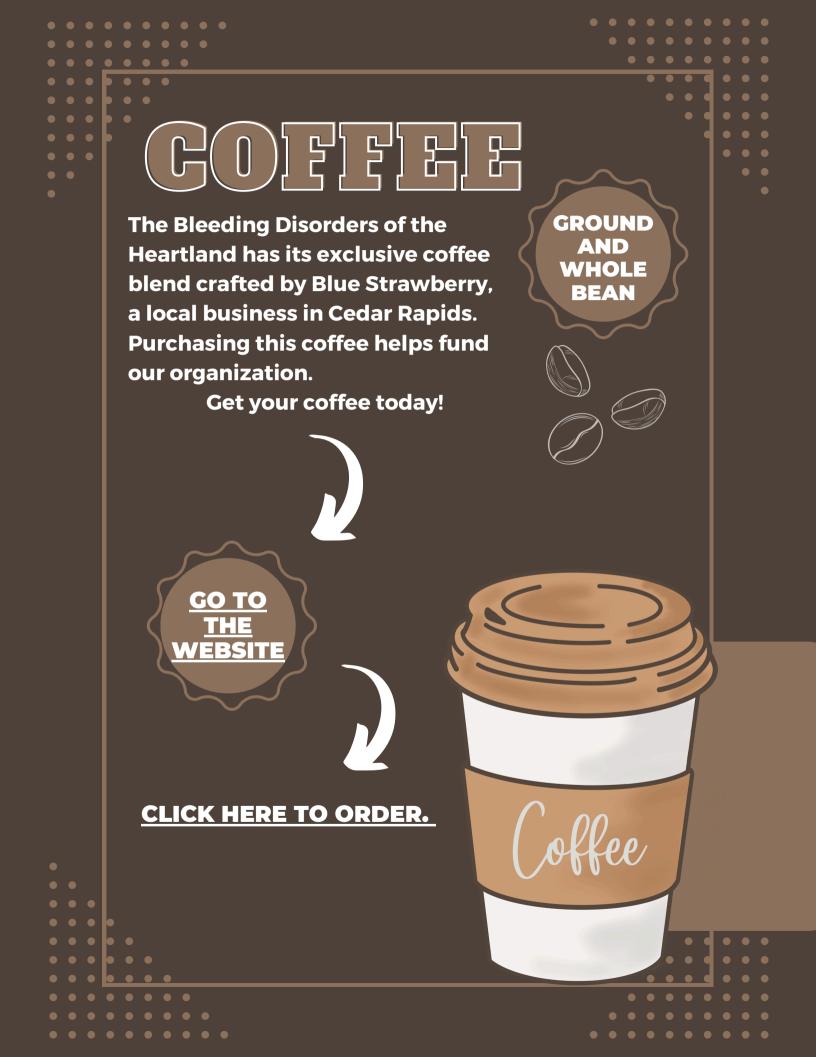
# BLEEDING DISORDERS AWARENESS MONTH





MARCH IS BLEEDING DISORDERS AWARENESS MONTH, AND WE'RE EXCITED TO ANNOUNCE THAT THE GOVERNOR HAS SIGNED A PROCLAMATION IN SUPPORT OF OUR COMMUNITY! THIS RECOGNITION HELPS RAISE AWARENESS ABOUT THE CHALLENGES FACED BY INDIVIDUALS LIVING WITH BLEEDING DISORDERS AND HIGHLIGHTS THE IMPORTANCE OF ADVOCACY, EDUCATION, AND ACCESS TO CARE. IT'S A POWERFUL MOMENT FOR OUR COMMUNITY, AND WE'RE GRATEFUL FOR THE GOVERNOR'S COMMITMENT TO BRINGING ATTENTION TO THIS IMPORTANT CAUSE. WATCH OUR FACEBOOK FOR POSTS TO SHARE ALL MONTH LONG.

For more information please visit the ADVOCACY tab at <u>www.bdheartland.org</u>





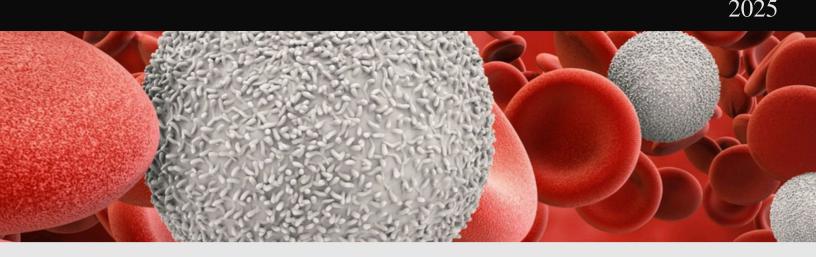
# HTC Corner

### Dedicated, Service Minded Nurses

We all know treatments for bleeding disorders are often lifelong. At University of Iowa Health Care, we provide life span care with a comprehensive approach. Our hematology team includes nurse coordinators, social workers, community nurses, physical therapists, dentists, genetic counselors, and pharmacists. This comprehensive team helps manage the social, emotional, and financial aspects of those affected by a bleeding disorder.

Our HTC Community Nurse Program extends the HTC care model into the community setting across the entire state to serve approximately 500 patients in mostly rural areas. There is a large and growing Amish population in Iowa, many of whom would otherwise receive infrequent care, if any, as long-distance transportation is difficult. Our nurses teach patients and families to manage chronic therapies at home. Services provided by the nurses include infusions/injections of treatment products, bleeding assessments, lab draws, patient, family, and community education and training, post-op/hospitalization assessments, pre/post out-patient procedure assessments, central line education and dressing changes, evaluation and coordination to ensure adequate home bleeding disorder medication and supplies. Through education and support, nurses empower patients and families to gain independence by learning skills they can perform at home. Our nurses help children as young as 6 years old take part in administering their prophylactic treatment product to foster ownership of their health.

Because of the passion and dedication of Angie, Tami, and Stacy, the HTC serves all of Iowa, reducing barriers to care and improving health outcomes.



### FDA Approves Subcutaneous Therapy for Hemophilia Patients with Inhibitors

Written by: Jonathan Angarola, Medical Programs, December 20, 2024

The U.S. Food and Drug Administration (FDA) has approved Alhemo (concizumabmtci) for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adult and pediatric patients 12 years of age and older with hemophilia A with factor VIII inhibitors or hemophilia B with factor IX inhibitors.

Alhemo is a subcutaneous therapy, which is developed using a synthetically produced (recombinant) antibody derived from a single cell clone, designed to be equally effective in individuals with hemophilia A and B, irrespective of inhibitor status. It targets an anticoagulant protein known as tissue factor pathway inhibitor (TFPI). It works by blocking and effectively preventing TFPI from performing the anticoagulant function that it naturally carries out in the human body. This type of therapy allows treaters to forgo the need for regular prophylaxis with traditional, intravenously infused factor replacement.

"The development of inhibitors remains the most serious treatment-related complication for people living with hemophilia. For patients with inhibitors, especially in hemophilia B, their hemophilia may remain poorly controlled and pose a life-threatening risk," said Amy Shapiro, MD, CEO and comedical director at the Indiana Hemophilia & Thrombosis Center, Inc. "The approval of Alhemo<sup>®</sup> – a first-of-its-kind, prophylaxis, subcutaneous injection pen for adults and children 12 years and older with hemophilia A and B with inhibitors – provides a muchneeded alternative to the current standard of care in hemophilia B with inhibitors, while offering patients with hemophilia A with inhibitors more treatment options, ultimately providing more patients with inhibitors the opportunity to personalize their care and address current treatment gaps."

Visit the <u>FDA website</u> to learn more about Alhemo, including the clinical trials that contributed to its approval.

Source: PR Newswire

Do you want to make your shopping even more meaningful this year? When you purchase gift cards through this special fundraising platform, a portion of the proceeds go back to BDH!

It's an amazing way to give back while still crossing off your gift list. There is no extra cost to you, it's just one simple way to support what we do. This will be available all year long.

### How it works:

Visit this link: https://www.raiseright.com/enroll/3XJTFTQBRLZZ Shop for gift cards to your favorite stores.

A portion of the proceeds benefits our organization—helping us continue our mission

### Get your shopping done and pay it forward!





https://bdheartland.org/events/annual-meeting-2/

# BLEEDING DISORDERS OF THE HEARTLAND'S FACTORING FAIRWAYS FOR FAMILIES 2025 GOLF EVENT!

# JUNE 2nd, 2025

Come enjoy a day on the course, raise awareness and funds for Bleeding Disorders of the Heartland. TOAD VALLEY GOLF COURSE 237 NE 80TH ST, PLEASANT HILL, IOWA 50327

SAVE THE DATE More information to come in 2025

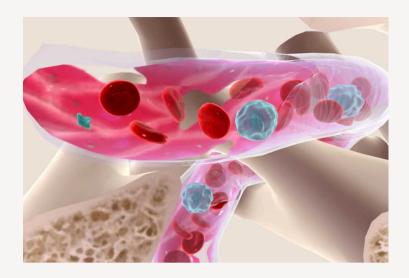
TOP SECRET Agents Only	https://bdheartland.org/eve nts/2025-bleeding- disorders-camp/
2025 BLEEDING	
DISORDERS SUMME	R CAMP
JUNE 15-20,2025	
Check the website for regist	
Camp Tanger, Mount	Vernon, IA

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### JANUARY 10, 2025 VWD THERAPY

### Investigational Sub-Q Von Willebrand Disease Therapy Put on Fast Track

The U.S. Food and Drug Administration (FDA) has granted Fast Track designation to the investigational von Willebrand disease (VWD) therapy VGA039. The therapy is being developed by Star Therapeutics, a biotechnology company based in San Francisco, CA.



VGA039 is a subcutaneously-delivered monoclonal antibody therapy designed to target Protein S as a means of restoring proper blood clotting in people with all types of VWD. An important regulator of clotting within the coagulation cascade, protein S works with other proteins in the body to prevent the formation of excessive blood clots.

Subcutaneous (Sub-Q) therapies require an injection just under the skin, as opposed to intravenously administered products which necessitate venous access. As an easier to administer therapy, Sub-Q treatments have the advantage of greater convenience which in turn may increase rates of adherence.

The new fast track designation follows <u>recent reporting</u> of positive interim clinical trial data for VGA039, which was presented during the 66th American Society of Hematology meeting in December 2024. FDA's Fast Track designation is meant to facilitate the development and expedite the review of drugs that treat a broad range of serious conditions and address an unmet medical need. The purpose is to get newer drugs in clinical development through FDA's approval process faster and ultimately to the patient earlier.

If VGA039 should receive FDA approval, it would be the first Sub-Q therapy to be available to treat all types of VWD.

"VGA039 is the first drug candidate to receive Fast Track designation for VWD, and we are committed to advancing drug innovation for this debilitating disease that has lagged behind other bleeding disorders," said Adam Rosenthal, PhD, CEO and Founder of Star Therapeutics. "Fast Track designation enables us to potentially accelerate the development path for VGA039 as a therapy that can transform the way VWD is treated with a convenient, subcutaneous therapy for patients with all types of VWD."

Learn more about Fast Track criteria and processes on the FDA website.

<u>https://www.bleeding.org/news/investigational-sub-q-von-willebrand-disease-therapy-put-on-fast-track?</u> <u>utm\_medium=email&utm\_source=mailchimp.com&utm\_campaign=NBDF%20News&utm\_term=Communications&utm\_content=25-</u> <u>01%20-%20FDA%20Grants%20Fast%20Track%20Status%20to%20VGA039%20for%20VWD</u> 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.

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### Empowering you to treat and manage your bleeding disorder

- Dedicated pharmacy transition support
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- In-home nursing support program for patient infusion education
- Assistance with prior authorizations. copay management and more

### See how we can help. PARAGONHEALTHCARE.COM/HEMO



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Becca Robbins **District Sales Manager** brobbins@paragonhealthcare.com 479.685.2532



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### WE TREAT THE WHOLE PERSON, NOT JUST THEIR SYMPTOMS.

### BCDI serves over 8,000 patients with ten outreach clinics across the state.

### **DISORDERS WE TREAT:**

- Hemophilia A & B
- ITP
- Von Willebrand Disease
- Clotting Factors
- Factor Deficiencies
- Platelet Function Disorder

Arthur

HSHS St. Mary's Hospital Building 525 N. Vine St. Arthur, IL 61911

Carbondale SIU Center for Family Medicine 300 W Oak St. Carbondale, IL 62901

Champaign OSF Medical Group – Primary Care 1405 W Park St., Suite 306 Urbana, IL 61820

Decatur Crossing Healthcare 320 E. Central Ave. Decatur, IL 62521

Macomb Medical Arts Building 527 E. Grant St. Macomb, IL 61455

Moline Pediatric Specialty Clinic 515 Valley View Drive Moline, IL 61265

#### Ottawa

Fox River Cancer Center 1200 Starfire Dr. Ottawa, IL 61350

#### Peoria

Bleeding & Clotting Disorders Institute 427 W Northmoor Dr.Peoria, IL 61614 Women's Service Clinics, Thrombophilia Clinics, and Immune Thrombocytopenic Purpura (ITP) Clinics are located at the Peoria location

Rockford OSF Saint Anthony Medical Center 5666 E. State St. Rockford, IL 61108

Springfield Springfield Clinic at St. John's Pavilion Dr. Brandt's Office 301 N 8th St -4th Floor, Springfield, IL 62701



www.ilbcdi.org 🔍

Phone: 309.692.5337 📋 Fax: 309.693.3913 💽 427 W Northmoor Rd. Peoria, IL 61614



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LOCATION TBD

Get ready for an unforgettable weekend of outdoor adventures, personal growth, and brotherhood at our Men's Retreat. Escape the hustle and immerse yourself in nature. This retreat is the perfect opportunity to reflect, recharge, and forge deeper connections with like-minded men. Whether you're seeking an adventure, or simply a chance to unwind, this retreat has something for everyone. Don't miss out on this exciting and transformative experience – we can't wait to see you there!

### **CSL Behring**

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**BLEEDINGDISORDERS** 

OF THE HEARTLAND

Nebraska Chapter NATIONAL BLEEDING DISORDERS FOUNDATION





### SAVE THE DATE

**REGISTRATION WILL OPEN CLOSER TO** THE EVENT WATCH THE WEBSITE

**\$20 for individuals** \$50 for families

# Family Education Day July 26,2025

# Waterloo, Jowg

Get ready for a wet and wild experience like no other, where the sun-soaked day is filled with laughter, thrills, and refreshing splashes.

Join Bleeding Disorders of the Heartland for a day filled with fun in the sun. Educational Program followed by time at the waterpark.

**ISIT THE EVENTS TAB ON THE** WEBSITE

319-721-1664



www.bdheartland.org

Financial Assistance available to those who qualify.

Contact us at bdh\_director@bdheartland.org if you need assistance.

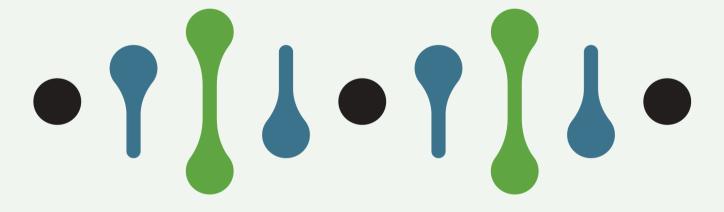


Suspension for intravenous infusion 1 × 10<sup>13</sup> vg/mL

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# ESCAPE THE ORDINARY. UNLOCK THE EXTRAORDINARY.

Join Bleeding Disorders of the Heartland on August 16–17, 2025 for an unforgettable experience at the 2025 Adult Retreat.



Save the Date More information will be available on the website under the events tab closer to the event.

# STEP RIGHT UP AND WALK FOR A CAUSE SEPTEMBER 27, 2025

BLEEDING DISORDERS OF THE HEARTLAND ANNUAL WALK

SAVE THE DATE

Bleeding Disorders of the Heartland Tel: (319) 721-1664 Email us at: bdh\_director@bdheartland.org



Bleeding Disorders of the Heartland 103 5th Ave Durant, Iowa 52747

Tel: (319) 721-1664 Fax: 615-900-1487 Email us at: bdh\_director@bdheartland.org



The Bleeding Disorders of the Heartland (BDH) asks for your contributions to support the programs and activities of BDH that focus on advocacy, awareness, education and mentorship of families and new families. You can make a financial contribution by going online to our website at www.bdheartland.org or by mailing your check to our office. Does your workplace offer an employee matching gift program? We have numerous fundraising events throughout the year that you can attend and financially support as well. Help us share the word about the mission of BDH.

### Thank you for making a difference!

This contribution is made in men	nory or honor of		
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Address:			
City:	State:	Zip Code:	

BDH is a nonprofit 501 © 3 organization that exists to enhance the lives of those affected with bleeding disorders.