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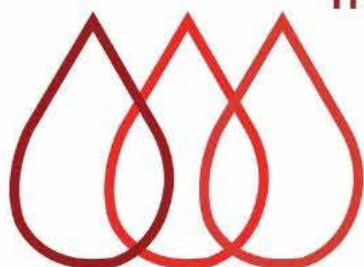
EDITOR  
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LOVING**



## BLEEDINGDISORDERS OF THE HEARTLAND

103 5TH AVE • DURANT, IOWA 52747 • 319-721-1664

**Scan the QR Code** provided below to access our website. Discover the latest information about our events, educational topics, contact details, and much more!



BLEEDINGDISORDERS  
OF THE HEARTLAND



# 2024 Capitol Day



Capitol Day was truly a remarkable experience for all who attended. It was inspiring to see 17 passionate individuals come together on February 7, 2024, to learn how to effectively use their voices to advocate for important causes and share their stories. The highlight of the day was undoubtedly when Governor Reynolds signed a proclamation that was then presented by Lieutenant Governor Gregg. It was a moment of validation and recognition for our collective efforts.

We are immensely grateful to everyone who participated and contributed to the success of Capitol Day. Your dedication and enthusiasm are truly commendable. As we reflect on this event, we are filled with gratitude and motivation to continue our advocacy work. The impact of our voices and actions is tangible, and we are excited about the possibilities that lie ahead.

Looking towards the future, we are already planning for next year's event with great anticipation. The momentum and energy generated from Capitol Day will serve as a driving force for our continued efforts. Together, we can make a difference and create positive change in our communities. Thank you once again to all who joined us, and let's keep working together to amplify our voices and advocate for a better tomorrow.



—————> [WWW.BDHEARTLAND.ORG](http://WWW.BDHEARTLAND.ORG)

# 2024 Capitol Day Sponsors



## CSL Behring



We are truly grateful for the generous support from our sponsors, CSL Behring and Takeda, who have made this event possible and have shown their commitment to our organization. A special thank you goes out to all the attendees who took the time to join us, learn, and advocate for themselves and their community. Your presence and participation make a significant difference, and together, we can create positive change and make a lasting impact.



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# NEW BOARD MEMBERS



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. Bleeding disorders have been a reality for all of Meg's life, even though she does not have the condition herself. Since she and her family have received the connections, education and resources from this organization, her goal is to give back and support the bleeding disorders community in any way she is able. She is excited to work with the board and make more friends and connections in the process!



NICK REUTER

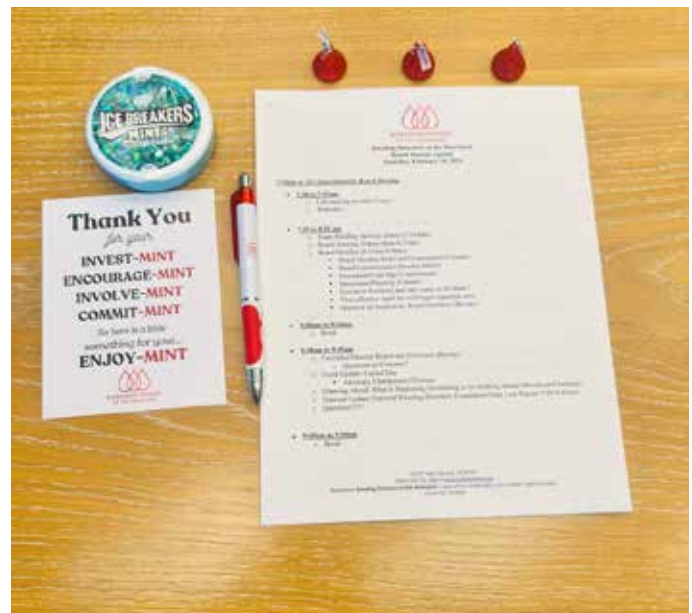
Nick is originally from Le Mars, Iowa and moved to the Des Moines area around 10 years ago. He's been married for nearly 5 years. He is a fan of the Iowa Hawkeyes and enjoy spending time with his friends and family when he gets the chance.

# 2024 February Board Retreat



The board members are dedicated individuals who bring a wealth of knowledge and experience to the table. They are all volunteers. Their commitment to the organization's mission is truly inspiring. The board retreat in Des Moines provided a great opportunity for them to brainstorm innovative solutions and strategies for the challenges ahead.

These retreats are designed to bring the team together in a setting away from the usual distractions of the everyday responsibilities. They offer a chance for board members to collaborate, brainstorm, and strategize in a more relaxed and focused environment. By stepping away from their daily routines, board members can gain new perspectives, build stronger relationships, and cultivate innovative ideas. Ultimately, board retreats can lead to increased efficiency, better decision-making, and a more cohesive team dynamic.



[WWW.BDHEARTLAND.ORG](http://WWW.BDHEARTLAND.ORG)



BLEEDING DISORDERS  
OF THE HEARTLAND

# 2024 Events

Exciting news and updates are just around the corner! Be sure to stay tuned to our website and Facebook page for the latest information on registration for upcoming dinners and events. Don't miss out on the chance to connect with like-minded individuals, indulge in delicious cuisine, and create lasting memories. Mark your calendars and get ready for some unforgettable experiences!

Annual Meeting

April 5-7  
Dubuque, Iowa

Annual Golf Event

June 10th  
Toad Valley Golf Course

Bleeding Disorders  
Camp

June 16th-21st  
Camp Tanager  
Mount Vernon, Iowa

Family Education Day

July 27th  
Burlington, Iowa

Adult Retreat

August 24th  
Des Moines, Iowa

# The HTC Corner

Submitted by Karla Watkinson, RN



## BLEEDING DISORDER CLINIC AVAILABILITY

Due to many reasons, finding open appointment times for our comprehensive clinics has been difficult. Currently, we are booking out greater than 6 months for our adult population and more than 8 months for our pediatric population.

For our patients who have severe bleeding disorders, we recommend an appointment every 6-12 months depending on the person, provider, and bleeding tendencies. For those with milder bleeding disorders, we recommend a return visit every 1-2 years.

If you are more than 2 years overdue for clinic, have not scheduled an appointment, or have numerous appointments you have missed, the doctors will not be able to continue making recommendations or writing prescriptions for your treatment.

Due to the difficulties in getting appointments, we encourage that you be diligent in keeping your scheduled appointments if possible. If you must cancel an appointment, please do so with as much time as possible so we can attempt to find another person to take your time slot.

If you have not scheduled an upcoming visit, please call to make them as soon as possible.

Please make sure if you call to schedule an appointment yourself, please make sure follow the guidelines below:

**Pediatrics:** Ask to be scheduled in a comprehensive hemophilia/bleeding disorder clinic and specify which provider you would like to see. The first Tuesday afternoon of the month is Dr. Sharathkumar's clinic and the second and third Wednesday morning is for Dr. Staber. Scheduling number for Pediatrics: 319-356-2229.

**Adults:** Ask to be scheduled in a Hemophilia slot and specify the provider. Dr. Lentz has clinics on the first and third Friday morning and Dr. Hsieh has clinic on the first and third Wednesday afternoon. Dr. Perepu is no longer here. The scheduling team will reach out to us if the appointment dates/times need to be sooner so we can look at the schedule to help fit you in earlier if needed. The scheduling number for Adults: 319-356-4200.

# The HTC Corner

Submitted by Karla Watkinson, RN

**FOR WOMEN AND GIRLS WITH A FAMILY HISTORY OF HEMOPHILIA**  
If you have sons, brothers, a father with hemophilia or you have hemophilia with a mother, sisters, or daughters, please urge them to have their factor levels checked by calling the Hemophilia team to discuss.

Many girls and women who are carriers may have lower than normal factor levels which may increase their risk of bleeding with surgery or injuries. We encourage you to call and discuss at 319-356-4277 and talk to one of our nurses.

## UNIVERSITY OF IOWA HEALTHCARE (UIHC AND SFCH) UPDATED VISITOR RESTRICTIONS: Beginning January 11, 2024

Due to the increase of viral infections such as RSV, Influenza, COVID, and other respiratory illnesses, the UIHC and SFCH have implemented new visitor guidelines including masking protocol.

### Inpatients:

- No visitors under 12
- 4 visitors per hospital stay.
- Visiting hours are 8 am to 8 pm.
- For Adult patients only 2 visitors are allowed on the inpatient unit at a time.
- For Pediatric patients 4 visitors are allowed on the inpatient unit at a time
- From 8 pm to 8 am:
- For Adult patients: 1 visitor is allowed overnight.
- For Pediatric patients: 2 visitors area allowed overnight.

### Surgery and Procedure Patients:

- 4 visitors/support persons per day; this is for both adults and pediatric patients.

### Outpatient Clinic Visits:

- Two visitors/support persons per day; both adults and pediatrics

### All Visitors:

- Must not have symptoms of a respiratory or other contagious illness.
- Should be a support person who is essential for the physical and mental well-being of the patient.
- Under age 14 must always be supervised by an adult
- Must stay in the designated areas such as the patient's room or clinic waiting area as much as possible.

Some areas may have other visitor guidelines to protect the health and safety of the patients.  
On SFCH Level 11

- Everyone must wear a mask upon entering onto level 11, including visitors, patients, and staff.

For more information, or to check for updates go to:  
[uihc.org/coronavirus](http://uihc.org/coronavirus)



## IMPORTANT ANNOUNCEMENT

As some of you may know, I went back to school to become a Nurse Practitioner. I finished my program last Summer. It is with great sadness that, after nearly 11 years, I will be leaving the HTC in February to start a new job as a nurse practitioner. I may have started my job as an HTC nurse 11 years ago, but I have known some of you for more than 20 years through Bleeding Disorder camp. While I am excited to start on a new journey it is bittersweet. I have found so much joy and purpose in this role. The bleeding disorder community is among the best group I've had the privilege to work with and felt like part of the family since day one. This is also one of the best medical teams I have worked with. I cannot express how amazing our hematologists, nurses, and rest of the comprehensive team are.

I want to thank each and every one of you for the impact you have made in my life. I wish you all the best. Even in 11 years, so many advancements have been made in the way we treat bleeding disorders, improving quality of life. There are so many good things to come. I am so proud and honored to have been a part of that. Being an HTC nurse has become my identity and my passion, I hope to some day find my way back to this community.

Michelle Krantz



### A note from the HTC-

As many of you know, Michelle Krantz, RN, BAN, our hemophilia nurse coordinator since 2013 went back to school to get her Doctorate in Nurse Practitioner (DNP). Our hope when she went back to school is that we would have a full-time position for her as a nurse practitioner on our Hemophilia/Bleeding Disorder team where she could see both pediatric and adult patients.

Due to circumstances beyond our control, funding is not available to finance this position.

With mixed emotions, Michelle will be leaving our team at the end of January or early February 2024 to pursue a new opportunity in her role as a DNP.

# **HFA 2024 SYMPOSIUM**

*Our Journey, Our Community* // // *Indianapolis*  
**CELEBRATING 30 YEARS**

***"Symposium was absolutely incredible,  
and I loved everything about it!  
The schedule was the right amount  
of education with just enough breaks so that  
I didn't feel exhausted or overwhelmed."***

*-2022 Symposium Attendee*

**Register now @ [www.HFASymposium.org](http://www.HFASymposium.org)**

**The clock is ticking! Rush to the website for all the details today. Don't miss out on this golden chance - attending could open doors to amazing opportunities.**

**Dive in and grab hold of the exciting adventures and rewards that await you!**



## **NATIONAL BLEEDING DISORDERS FOUNDATION ANNOUNCEMENT:**

We are honored to share that Phil Gattone has been named our next president and CEO. He'll take the helm Feb. 12 to help advance NBDF's focus of innovative, inclusive research, education, and advocacy for the inheritable blood and bleeding disorders community.

"This is an era of unprecedented opportunity, and I look forward to continuing to grow NBDF's impact and capacity to serve our community," Gattone said. "Together, we will break down barriers to better health and equity, and create resilient, inclusive communities where everyone can thrive."

Gattone succeeds Len Valentino, MD, NBDF's president and CEO since 2020. During his four-year tenure at NBDF, Valentino helped organize programs and events such as the first Health Equity Summit, the Research State of the Science, National Research Blueprint, and Pathway to Cures.



**Welcome!**

Phil Gattone, M.Ed.,  
President and CEO, NBDF

 NATIONAL  
BLEEDING DISORDERS  
FOUNDATION  
*Formerly NHF*

**NBDF 2024 CONFERENCE IS IN SEPTEMBER  
IN ATLANTA GEORGIA  
YOU CAN FIND INFORMATION ON THEIR WEBSITE  
[WWW.HEMOPHILIA.ORG](http://WWW.HEMOPHILIA.ORG)**

## Bleeding Disorders of the Heartland Annual Meeting Join us April 5-7th in Dubuque, Iowa at Grand Harbor Waterpark and Resort

Get ready to mingle with our fabulous bleeding disorders fam! Meet other folks who totally get what it's like to rock life with a bleeding disorder.

We've got a jam-packed weekend filled with fun and connection galore, including a splash-tastic water park! You'll get the latest scoop on bleeding disorder news, both local and national, through our super cool educational sessions and breakout discussions.

If you're a newbie to the bleeding disorder crew, fret not! We've set aside special support time just for you, for up to 8 years post-diagnosis. Plus, we'll update you on all things Bleeding Disorders of the Heartland and HTC!

For the parents out there, we've got your back too. Our child care crew are experts in all things bleeding disorders, so you can relax and learn knowing your kiddos are in fantastic hands.

This is just the tip of the iceberg!  
We've got so much more in store, so come join us and let's make some unforgettable memories together!





# JUNE 10TH, 2024

# SAVE THE DATE

# 2024 GOLF EVENT!

Come enjoy a day on the course and raise awareness and funds for Bleeding Disorders of the Heartland.

**TOAD VALLEY GOLF COURSE 237 NE 80TH ST, PLEASANT HILL, IOWA 50327**

Watch the website or Facebook for details

[www.bdheartland.org](http://www.bdheartland.org)



## Explore Head-to-Head Pharmacokinetic (PK) Study Data

See half-life, clearance, and other PK data from the crossover study comparing Kovaltry® and Advate®.

Visit [Kovaltry-us.com](https://www.kovaltry-us.com) to find out more.

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 **Kovaltry®**

Antihemophilic Factor (Recombinant)

Registration is coming up for Bleeding Disorders Camp. Keep your eyes on the website or FaceBook in April.

Camp was so much fun! You got to make lots of friends!  
-Quincy 10

I felt normal when at camp with kids just like me. I can't wait to come back next year.  
-16 year old  
Scan the QR code to view a video





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**ROCTAVIAN  
clinical study  
participant**



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# H-Fit

with Dolvett Quince

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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# CSL Behring

Biotherapies for Life™

**Proud to serve the bleeding disorders community with the latest technologies, innovative therapies and support.**



**Mike Appleseth**

**Manager, Coagulation Products**

**641-757-0499 / [mike.appleseth@cslbehring.com](mailto:mike.appleseth@cslbehring.com)**

**Serving Iowa, Nebraska, Kansas and Missouri**

# WHAT'S NEXT? YOU DECIDE.



At Genentech, we're committed to creating programs for you, with you. From a web series focused on finding the *magic* in life, to a tournament for gamers, to workshops designed to help you think well, do well, and be well, we're here to help you take on what comes next.

VISIT [GENENTECHHEMOPHILIA.COM](https://www.genentechhemophilia.com)  
TO SEE HOW WE'RE CREATING  
WHAT'S NEXT, TOGETHER.

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**GENENTECH IN  
HEMOPHILIA**

**Genentech**  
*A Member of the Roche Group*





# SWITCH IT UP like Joey did!

a real ALTUVIIIIO patient

Joey has been compensated for sharing his story.

Sanofi Community Relations and Education (CoRe) Managers are dedicated professionals who can provide personalized education about ALTUVIIIIO, and point you toward helpful support and resources.



## CONNECT WITH YOUR CoRe TODAY

## Family Tradition Gives Back to Local Chapter



The Meyer family held its annual Christmas family celebration on December 23rd. We spend the day together enjoying LOTS of food, gift giving, and laughter. Every year we play a family game. Each adult donates \$20 to play. This year, all of the money is being donated to Bleeding Disorders of the Heartland. We played Christmas Charades, with 4 generations of Meyers playing! We had SO much fun! Bill and I have been members of Hemophilia of Iowa, now renamed, since around 1985. We have 2 sons with hemophilia, and I have Von Willebrands. This is an amazing organization! I've served on the BOD and organized the first golf tournament. We have made many "forever" friends! We are thrilled to be able to donate \$800! Why not do the same in your family! Happy New Year!

Carol Meyer



# We need YOU!



**BLEEDING DISORDERS  
OF THE HEARTLAND**

**BLEEDING DISORDERS OF THE HEARTLAND  
is expanding our board of directors.**

**Do you know someone with legal expertise, tax  
knowledge, CPA certification, or board experience?  
We are actively searching for qualified individuals  
to join our board of directors and help us grow.**



**Scan the QR Code to donate or contact BDH**

**Are you able to assist us in Diversifying Funding ?  
We're seeking your assistance! Do you have funds available for  
donation or know of companies or organizations that are  
interested in supporting a good cause or looking for a tax write-  
off? We're looking to diversify our funding sources.**

**Additionally, have you formed a walk team yet? It's never too early  
to begin raising funds to help our organization advance its  
mission to educate, connect, and support those affected with  
bleeding disorders.**

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**Visit [www.bdheartland.org](http://www.bdheartland.org)**



The medical information contained in this newsletter is for information purposes only and is not to be taken as medical advice. If you have any questions or concerns, always check with your healthcare provider.



## BLEEDING DISORDERS OF THE HEARTLAND

103 5TH AVE  
DURANT, IOWA 52747

### Candidates Sought for Board of Directors

Although candidates for the Board can contribute through a variety of ways, we are looking for experience and skills in the following areas:

- Leadership
- Non-profit organizations
- Facilitation skills
- Public relations/marketing
- Legal

If you or someone you know is interested in serving on Bleeding Disorders of the Heartland's Board of Directors, please contact the us at [bdh\\_director@bdheartland.org](mailto:bdh_director@bdheartland.org) or 319-721-1664.