

# Rhinestones & Resilience



**Shining Bright, Standing Strong,  
and Making A Difference**

**Annual Meeting 2025**

# Rhinestones & Resilience

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## **A Heartfelt Thank You to Our Sponsors**

We extend our deepest gratitude to all our sponsors.  
Your support has been instrumental in making our  
Annual Meeting a great success.

Make sure to visit each booth!!

# Rhinestones & Resilience

## Welcome to the 55th Annual Meeting

Welcome to the 55th Annual Meeting of the Tennessee Hemophilia & Bleeding Disorder Foundation. We are thrilled to gather with you this year at the beautiful HeartSong Lodge at Dollywood, a truly special place to celebrate the strength and unity of our community.

For 55 years, this meeting has been a cornerstone of connection, support, and shared purpose. It's a time for reflection, learning, and celebrating the progress we've made together. This weekend represents the heart of who we are: individuals and families who lift each other up, advocate for access to care, and believe in a future full of hope.

We would like to extend our deepest gratitude to our Board of Directors, whose dedication and vision make this event and all our work possible. We are also especially thankful for the tireless efforts of our staff and volunteers, whose passion and hard work behind the scenes ensure that this weekend is meaningful, engaging, and unforgettable.

Whether this is your first time attending or your 20th, thank you for being here. You are an important part of this incredible community, and we are so glad to share this experience with you.

With gratitude,  
The THBDF Team

# **Rhinestones & Resilience**

## **Committee & Volunteers**

### **Committee Members**

Shannon Cassada

Ashley Lacy

LeAnn Wilson

Anne-Louise Wirthlin

### **Childcare Leaders**

0 - 4 year olds

Barbara Rodgers

5 - 12 year olds

Anne Louise Wirthlin

13 - 17 year olds

Brittany Chaney

### **Volunteers**

Treleisha Caldwell

Shannon Cassada

Darry Chaney

Mary Crow

Haven Czyszczak

Andrea Edwards

Ashley Lacy

Marie Prince

Barbara Rodgers

Miracle Walls

David Wilson

Haylee Wilson

Hudson Wilson

LeAnn Wilson

Anne-Louise Wirthlin

Chad Wright

***We would like to thank our committee and volunteers  
for all the hard work they put into during our Annual  
Meeting. We could not do this without them!!***

# Rhinestones & Resilience

## Agenda

### **FRIDAY, JULY 25TH**

Hotel check-in 4:00 pm (EST)

Event check-in 5:00 pm (EST)

**6:00 - 8:00 pm Exhibit Hall Open**    *HeartSong Ballroom*

**6:30 - 7:30 pm Dinner Reception**    *HeartSong Ballroom*

### **7:30 - 8:00 pm Childcare Registration and Check in**

0 - 4 year olds                      *(check with THBDF Registration)*

5 - 12 year olds                      *Inspiration C*

13 - 17 year olds                      *Inspiration D*

### **8:00 - 9:00 pm Rap Sessions**

Blood Brotherhood                      *Inspiration B*

Beside the Brave                      *Outdoor #13 Firepit*

Women's Initiative                      *Inspiration A*

### **9:00 - 9:15 pm Childcare Pick Up**

0 - 4 year olds                      *(check with THBDF Registration)*

5 - 12 year olds                      *Inspiration C*

13 - 17 year olds                      *Inspiration D*

### **SATURDAY, JULY 26TH**

**7:30 - 8:30 am Breakfast**                      *HeartSong Ballroom*

### **8:00 - 8:30 am Childcare Check-in**

0 - 4 year olds                      *(check with THBDF Registration)*

5 - 12 year olds                      *Inspiration C*

13 - 17 year olds                      *Inspiration D*

# Rhinestones & Resilience

## Agenda

### SATURDAY, JULY 26TH CONTINUED

#### **8:00 - 8:30 am Path Finders**

*Inspiration D*

This is a meeting for all the 13 - 17 year olds **(and their parents)** and the young adults.

**Sponsored by: GutMonkey and Sanofi**

#### **8:45 - 9:00 am THBDF Welcome**

*HeartSong Ballroom*

Speakers: Janet Patterson - Board President,  
Amanda Willson - Executive Director, and Megan  
Crow - Advocacy Committee Chair

#### **9:00 - 10:00 am Exhibit Hall Open**

*HeartSong Ballroom*

#### **10:10- 11:10 am Breakout Session 1**

Prophylaxis Option for Adults and  
Adolescents Who Have Hemophilia with Inhibitors

*Inspiration A*

*Speaker: Bradley Odac*

**Sponsored by: Novo Nordisk**

Kinesiology Tape

*Inspiration C/D*

*Speaker: Alice Anderson, PT, DPT, MS, PCS*

**Sponsored by: Optum**

Finding Your Harmony

*Inspiration B*

*Speaker: David Tignor*

*Sponsored by: BioMatrix*

# Rhinestones & Resilience

## Agenda

### **SATURDAY, JULY 26TH CONTINUED**

#### **11:15- 12:00 pm General Session**

Beyond the Needle

*HeartSong Ballroom*

*Speaker: Robin Cunningham*

**Sponsored by: Sanofi**

#### **12:00 - 1:00 pm Lunch Break**

*HeartSong Ballroom*

#### **1:15- 2:15 pm Breakout Sessions 2**

Balancing Emotional Wellness

*Inspiration C/D*

*Speaker: Robert J. Meijer -Patient Navigator*

**Sponsored by: Pfizer**

QFit

*Inspiration A*

*Speaker: Cassandra Titus*

**Sponsored by: Sanofi**

Investigational Subcutaneous  
Treatment For VWD

*Inspiration B*

*Speaker: Chuka Didgu, MD, PhD, Medical Director,  
Clinical Development*

**Sponsored by: Star Therapeutics**

#### **2:15 - 3:15 pm Exhibit Hall is Open** *HeartSong Ballroom*

#### **3:30 -4:30 pm Breakout Sessions 3**

Hympavzi: Understanding a

*Inspiration C/D*

Rebalancing Therapy Option for Hemophilia

*Speaker: Robert J. Meijer - Patient Navigator*

**Sponsored by: Pfizer**

# Rhinestones & Resilience

## Agenda

### SATURDAY, JULY 26TH CONTINUED

#### **3:30 -4:30 pm Breakout Sessions 3**

Advocating For Your Children *Inspiration A*

*Speakers: Jessica Goddard, CCLS  
and Caprice Riley, MSW*

**Sponsored by: Vanderbilt HTC**

Women Matter in Bleeding Disorders *Inspiration B*

*Speaker: Morgan Cook*

**Sponsored by: Takeda**

#### **4:30 - 4:45pm Childcare Pick Up**

0 - 4 year olds *(check with THBDF Registration)*

5 - 12 year olds *HeartSong Ballroom*

13 - 17 year olds *HeartSong Ballroom*

**4:45- 5:00 pm Snack Break** *HeartSong Ballroom*

**5:00 - 5:30 pm Closing and Awards** *HeartSong  
Ballroom*

**5:30 pm Group Photo** *HeartSong Ballroom*



# Rhinestones & Resilience

## Session Descriptions

### FRIDAY, JULY 25TH

#### **Rap Sessions**

8:00 - 9:00 pm

Rap Sessions provide unique opportunities to talk with others whose situations and interests are similar to yours. Each group will have a facilitator.

#### **Blood Brotherhood - Inspiration B**

For men ages 18 and older with a bleeding disorder.

*Speaker: David Tignor*

#### **Beside the Brave - Outside Firepit #13**

For the men who walk alongside- supporting, encouraging, and standing strong for those living with bleeding disorders.

*Speakers: Amanda Wilson*

#### **Women's Initiative - Inspiration A**

For women 18 and older. Get your creative side going and decorate a Trucker Hat in, of course, Dolly fashion!

*Speaker: LeAnn Wilson*

### SATURDAY, JULY 26TH

#### **Welcome to the 55th Annual Meeting**

8:45 - 9:00 am - *HeartSong Ballroom*

You will hear about our Foundation and where it is heading.

*Speakers: Janet Patterson, BOD President,  
Amanda Wilson, Executive Director  
Megan Crow, Advocacy Committee Chair*

# Rhinestones & Resilience

## Session Descriptions

### SATURDAY, JULY 26TH CONTINUED

#### **Prophylaxis Option for Adults and Adolescents Who Have Hemophilia with Inhibitors**

10:10 - 11:10 am - *Inspiration A*

*Speaker: Bradly Odac*

#### **SPONSORED BY NOVO NORDISK**

Learn more about a subcutaneous prophylactic treatment option in a prefilled injection pen for adults and adolescents who have hemophilia B or A with inhibitors. This engaging presentation will provide an overview of this product. We'll discuss its clinical studies, safety, efficacy, and mechanism of action. We'll also explore this product's innovative pen design.

#### **Kinesiology Tape (K-tape)**

10:10 - 11:10 am - *Inspiration C/D*

*Speaker: Alice Anderson, PT, DPT, MS, PCS*

#### **SPONSORED BY OPTUM**

This workshop will teach you about kinesiology tape. Topics explore the makeup and uses for this therapeutic tape. Discussion includes how professionals may also use it. Individuals also learn how to apply and safely remove k-tape. The session includes a demo and hands-on interaction.

# Rhinestones & Resilience

## Session Descriptions

### **SATURDAY, JULY 26TH CONTINUED**

#### **Finding Your Harmony**

10:10- 11:10 pm - Inspiration B

*Speaker: David Tignor*

#### **SPONSORED BY BIOMATRIX**

Finding your harmony focuses on identifying and understanding the difference between anxiety and stress and how these can affect a person's health and life in general. Tips and techniques are provided on dealing with complicated situations, as well as learning new skills on how to deal with anxiety and stress.

#### **Beyond the Needle**

11:15 - 12:00 am - *HeartSong Ballroom*

*Speaker: Robin Cunningham*

#### **SPONSORED BY SANOFI**

Robin has been a Hemophilia Clinical Educator (CE) at Sanofi for 2 years, since the inception of the CE Team in 2023, and has been with Sanofi for over 10 years. In this role, CE's provide product, administration & disease state education to Sanofi hemophilia patients & caregivers. By training, Robin is a nurse with over 30 years of experience in multiple disciplines, including participating as an adjunct professor for several colleges. She currently lives in Atlanta, Georgia & finds inspiration through helping patients and caregivers become better self-advocates and self-caregivers through the education she offers.

# Rhinestones & Resilience

## Session Descriptions

### **SATURDAY, JULY 26TH CONTINUED**

Looking Beyond the Needle for an essential understanding of five components that can impact the infusion experience- vein anatomy, self-assessment technique, mental preparation, infusion tips, and infusion fatigue. A Clinical Educator (CE) will facilitate an interactive discussion & activity to help attendees maximize success with at-home infusions.

#### **Balancing Emotional Wellness**

1:15 - 2:15 pm - Inspiration C/D

*Speaker: Robert Meijer, Patient Navigator*

#### **SPONSORED BY PFIZER**

An overview of how emotional health impacts the hemophilia community, what signs/symptoms to look for, and how to encourage dialogue with caregivers and health care providers.

#### **Qfit**

1:15 - 2:15 pm - *Inspiration A*

*Speaker:*

#### **SPONSORED BY SANOFI**

This presentation is about a new rebalancing treatment delivered by subcutaneous injections for Hemophilia A and B.

# Rhinestones & Resilience

## Session Descriptions

### **SATURDAY, JULY 26TH CONTINUED**

#### **Investigational Subcutaneous Treatment for VWD**

1:15- 2:15 am - Inspiration B

*Speaker: Chuka Didigu, MD, PhD, Medical Director, Clinical Development at Star Therapeutics*

#### **SPONSORED BY STAR THERAPEUTICS**

Star Therapeutics is developing a subcutaneous, prophylactic treatment for VWD called VGA039. VGA039 is not a factor replacement therapy; it is an engineered antibody that binds to a specific protein in blood called Protein S to rebalance the coagulation system in patients with VWD. Because of its long half-life, VGA039 can be dosed infrequently, and because VGA039 does not interact with VWF, patients of all VWD types and subtypes may be eligible for treatment. This session will introduce patients to how a novel treatment like VGA039 works and review results from the initial clinical trial, and share how interested individuals may learn more about the VBega Program and potentially participate in current and future VGA039 clinical trials.

#### **Women Matter in Bleeding Disorders**

3:30- 4:30 pm - Inspiration B

Speakers: Morgan Cook

#### **SPONSORED BY TAKEDA**

Women with bleeding disorders face unique challenges that are often unrecognized or underappreciated. Understand some of the special challenges faced by women with bleeding disorders and identify options for emotional support within the community.

# Rhinestones & Resilience

## Session Descriptions

### **SATURDAY, JULY 26TH CONTINUED**

#### **Humpavzi: Understanding a Rebalancing Therapy Option for Hemophilia**

3:30 - 4:30 pm - *Inspiration C/D*

*Speaker: Robert J. Meijer, Patient Navigator*

#### **SPONSORED BY PFIZER**

In this session, we'll dive into a rebalancing treatment option. From how it works to clinical trial learnings, you'll gain the latest information to help you or your loved ones understand this treatment option with confidence.

#### **Advocating For Your Child**

3:30 - 4:30 pm - *Inspiration A*

*Speakers: Jessica Goddard CCLS and  
Caprice Riley MSW*

#### **SPONSORED BY VANDERBILT HTC**

As a parent or caregiver, you are your child's strongest advocate, at school, in medical settings, and beyond. This session will empower you with tools, strategies, and confidence to speak up and ensure your child's needs are met. We'll explore real-life scenarios, share practical tips for working with schools and healthcare providers, and discuss how to navigate common challenges such as IEP/504 plans, emergency care protocols, and preparing your child to self-advocate as they grow. Whether you're new to this journey or looking to strengthen your advocacy skills, this interactive session will leave you informed, encouraged, and equipped.

# Rhinestones & Resilience

## Infant and Toddler Program Schedule

**ages 0 - 4: (TBD)**

Please submit all necessary paperwork to enroll your child(ren) in the childcare program.



### **Friday, July 25th**

8:00 pm Drop Off

9:00 pm Pick Up

### **Saturday, July 26th**

8:00 am Drop Off

4:30 pm Pick Up

This age group will have a fantastic day filled with fun toys and engaging activities. We will provide lunch and snacks for everyone. Please ensure you bring ample supplies for your child, including diapers, a change of clothes, their favorite blanket, and more. We kindly request that you do not enter the rooms to check on your children throughout the day. If you prefer, we would be happy to send you text updates on your child's progress. If you wish to pick up your child early, please notify the childcare staff in advance so they can gather your child's belongings and meet you outside the room.

**Please check with THBDF registration to know which room the small children will be in.**

# Rhinestones & Resilience

## Kids Program Schedule

### ages 5 - 12 - Inspiration C

Please submit all necessary paperwork to enroll your child(ren) in the childcare program.



### **Friday, July 25th**

8:00 pm Drop off

9:00 pm Pick Up

### **Glow-in-the-Dark Party**

Your kids will have a great time dancing, playing limbo, twister, tic tac toss, tumble tower, and just hanging out with their friends.

### **Saturday, July 26th**

8:00 am Drop off in the Inspiration C/D

10:00 am Bus leaves for MagiQuest

2:30 pm Bus picks up from MagiQuest

4:30 pm Check out in the HeartSong Ballroom

### **MagiQuest**

Your kids will have a great time at MagiQuest with the interactive, live-action role-playing game where players use a magic wand to solve quests and interact with a themed environment.

**Lunch and snacks are included; please do not send any cash with them. They will need comfortable walking shoes and the THBDF t-shirt they received when registering.**



# Rhinestones & Resilience

## Teen Program Schedule

ages 13 - 17 - Inspiration D

Please submit all necessary paperwork to enroll your child(ren) in the childcare program.



### **Friday, July 25th**

8:00 pm Drop Off

9:00 pm Pick Up

Your kids will have a chance to hang out with their friends.

### **Saturday, July 26th**

8:00 am Drop off and Meeting with GutMoney  
(Parents must attend) in Inspiration A

8:30 am Bus leaves for Patriot Park Island

4:00 pm Bus picks up from LazerPort

4:30 pm Check out in the HeartSong Ballroom

This group will kick off the morning with GutMonkey's Path Finders Program sponsored by GutMonkey and Sanofi. Following the hike, we'll enjoy lunch together before heading to LazerPort Fun Center, home of the tallest go-kart track, blacklight mini golf, and laser tag.

**Lunch and snacks are included; please do not send any cash with them. They will need comfortable walking shoes and the THBDF t-shirt they received when registering.**

# Rhinestones & Resilience

## Young Adults Program Schedule

**ages 18 - 26 - Inspiration D**

Please be sure to sign the GutMonkey PathFinders  
Authorization Form

### **Saturday, July 26th**

8:00 am Meeting with GutMonkey in  
Inspiration A

8:30 am Bus leaves for Patriot Park Island

3:30 pm Bus picks up from Escapology

This group will kick off the morning with GutMonkey's Path Finders Program sponsored by GutMonkey and Sanofi. Following the hike, we'll enjoy lunch together before heading to Escapology, where you'll collaborate as a team to solve puzzles and uncover clues in themed escape rooms.

Themed Rooms include:

1:45 pm - Scooby Doo

1:55 pm - Lost City

2:05 pm - Mansion Murder

2:15 pm - Batman

2:25 pm - Murder on the Orient Express

2:30 pm - Who Stole Mona?

# Rhinestones & Resilience

## Games / Awards

### Bingo

On Friday, during the reception, you will receive a bingo card featuring various items to look for. Your task is to find someone who fits the description in each box and have them initial it. Once your card is completed, turn it in at the THBDF booth or registration desk for a chance to win a \$50 Amazon gift card. **Remember to write your name on the back!**

### Tickets

You will receive tickets that can be used for prizes. Exhibitors will distribute tickets when you visit their booths. There will be three designated times to collect tickets, and you're welcome to visit more than once. Note that this is for adults only; attendees aged 17 and under will receive a booth stamp instead. We will hold one drawing for the booth stamp for a \$50 Amazon card, along with three drawings for the tickets for a \$50 Amazon card.

### Assortment of Fun Baskets

We will have a variety of exciting baskets for which tickets will be drawn. You will have the chance to purchase tickets to enter and win your favorite basket(s). Tickets will be available for sale during exhibit times.

**1 ticket = \$5**

**5 tickets = \$20**

# Rhinestones & Resilience

## THBDF Program Services

### Camp Freedom

One of the programs in which the Foundation is most proud is summer camp for children ages 7 - 15 years. Camp Freedom gives kids with a bleeding disorder, and their siblings, a chance to engage in fun and exciting activities while also learning to “stick” themselves to infuse their medication, encouraging independence and prevention of joint disease. Camp is provided at no cost to families who live in Tennessee or go to a Tennessee Hemophilia Treatment Center.

### Blood Brotherhood Program

This program is for men ages 25 and up. The objective of the Blood Brotherhood program is as follows:

***Social Support*** - Increase participation in bleeding disorder-related activities, communication with peers, and coping skills.

***Optimize Health Care*** - Participants will be encouraged to take advantage of care offered through a Hemophilia Treatment Center.

***Physical Health*** - Increase the understanding of how physical activity improves health and prevents disease and complications associated with bleeding disorders and aging.

# Rhinestones & Resilience

## THBDF Program Services

### **Family Adventure Weekend**

Join us for a fun-filled and memorable Family Adventure Weekend at Deer Run! This special weekend offers families the chance to experience all the joys of camp together in a beautiful outdoor setting.

Families will stay in cozy cabins, enjoy delicious meals together in the camp's mess hall, and participate in a variety of exciting activities, from swimming in the lake to testing your skills in archery, basketball, wall climbing, and zip lining. There's something for everyone to enjoy!

While the kids are having a blast outdoors, parents will have the opportunity to attend educational sessions focused on topics relevant to the bleeding disorder community. It's a perfect blend of learning, relaxation, and adventure all designed to strengthen family bonds and build community.

### **Women's Initiative**

This is an outlet for women and girls, ages 18 and over, with bleeding disorders and women affected by a bleeding disorder (i.e. wives, mothers). Our mission: "To unite and support women affected by a bleeding disorder through informational programs, advocacy, and social events."

# Rhinestones & Resilience

## THBDF Program Services

### **Family Fun Nights**

This is an opportunity for families to get together in their area and enjoy a fun activity. Some of the activities that we have done are: Nashville Sounds Game, Predators Hockey Game, Deck the Diamonds Lights, Sleeping with the Sharks. Be sure to keep an eye out for some in your area!

### **Fall Festival**

Fall is a great time to get outside and spend time with your family and friends at a corn maze. We move this event each year to a different part of the state. This year will be Memphis!

# **Rhinestones & Resilience**

## **Calendar of Events**

### **Family Adventure Weekend**

Date : August 15 - 17, 2025

Location: Deer Run Retreat

Thompson Station, TN

### **Fall Festival**

Date : September 27, 2025

Location: Kyker Farms

Seiverville, TN

### **Camp Freedom Reunion**

Date: October 16 - 19, 2025

Location: Brandon Springs Group Center

Dover, TN

### **Women's Initiative**

Date: January 29 - February 1, 2026

Location: Santa Rosa Beach, FL

### **Blazin' for Bleeders**

Date: April 26, 2026

Location: Murfreesboro, TN

Don't forget to sign up for our weekly emails to see all the dinner programs and family fun nights!! Or you can visit our website at [www.thbdf.org/programs-events](http://www.thbdf.org/programs-events).

# Rhinestones & Resilience

## Ways to Stay in the Know!

We have several ways we try to keep the community current on upcoming programs and events. Scan the QR codes below to sign up and stay in the KNOW!

- **Weekly Email** that is updated regularly that has all upcoming programs, events, available scholarships, dinners and family fun nights with an easy registration button to RSVP for the event.



- **The Pulse Newsletter** is published 3 times a year. This newsletter provides recaps on all programs and events, upcoming events, advocacy information, and so much more.



- **THBDF website** has been working on updating our website with information on events, programs, and bleeding disorders including a new section called *Women Who Bleed*. Be sure to go our website and check it out!!





# **Rhinestones & Resilience**

## **More information...**

**We have a limited amount of Tennessee Hemophilia & Bleeding Disorders t-shirts for sale during the Exhibit hours. Please come and see us for your shirt!**

**\$15 - Youth Sizes**

**\$20 - Adult Sizes**

**Vote for your favorite decorated booth by scanning the QR code below!!**



**Please share your thoughts on our 55th Annual Meeting. Scan the QR code below to complete an evaluation, which will help us identify areas for improvement.**



# Rhinestones & Resilience

## **Contact Information**

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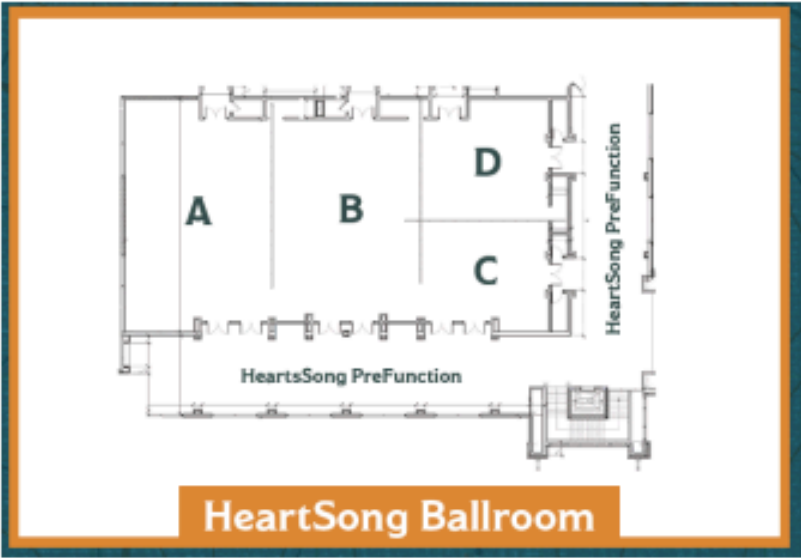
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# Rhinestones & Resilience

## Lobby Level



## Ground Level

