

THE BCDI BEACON

THE BLOOD EXPERTS NEWSLETTER

NOVEMBER 2024 EDITION

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*The Blood
DROP Society's
Inaugural Event*

*Educational Dinner
with Dr. Roberts*

*Staying Healthy
Through the Winter*



IN THE SPOTLIGHT

Dr. Tarantino Wins NBDF Lifetime Achievement Award

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A MESSAGE FROM **DR. TARANTINO**

BCDI Chief Executive Officer
BCDI Chief Medical Officer



The mission of The Bleeding & Clotting Disorders Institute is to provide integrated, family-oriented care, treatment and education for individuals with bleeding, blood clotting and other blood disorders. As the only federally funded Hemophilia Treatment Center of Excellence in the state of Illinois outside of Chicago, we strive to deliver exceptional care for each person we serve.

The BCDI Foundation was created in 2022 with the goal of enhancing support and resources available for BCDI to improve the lives of individuals affected by bleeding, clotting or other blood disorders. The mission of the BCDI Foundation is to raise crucial funds and awareness for the services BCDI supplies beyond our clinic walls, including scholarships, education, research support, financial aid and other community-focused initiatives. The BCDI Foundation aims to create a sense of community among patients, families, and advocates.

BCDI was honored to host the 2024 BCDI Golf Outing in August 2024, which was our first event with all proceeds directly benefitting the BCDI Foundation. As we set out sights on 2025 and beyond, please note that proceeds from all BCDI fundraising events will go directly to the BCDI foundation to support the needs of our patients. This is our promise to our community we serve: to strive for optimal patient outcomes; better quality of lives for our patients; and to be a pioneer in research and advocacy for the bleeding disorders community.

In October 2024, we were honored to unveil the brand new BCDI Foundation logo, seen here. This logo is an adaptation of the classic BCDI "Blood Huggers" logo but provides a new meaning. To learn the full story behind the BCDI Foundation logo and for more information on how you can be involved with the BCDI Foundation, please scan the QR code or visit our new BCDI Foundation website: www.bcdifoundation.org.



FOUNDATION
Supporting the Bleeding & Clotting Disorders Community



BEACON BUZZ

BCDI BLOOD DROP SOCIETY

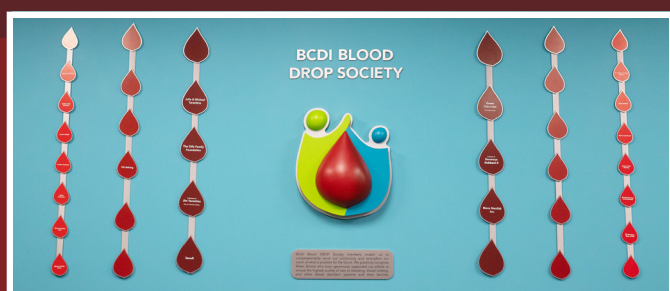
We are excited to announce the launch of the BCDI Blood DROP Society, which is a donor membership recognition that provides funding to help support BCDI's mission. At BCDI, our number one priority is to provide optimal outcomes for our patients and their families. BCDI relies on the philanthropy of our community to help us fulfil our goal of providing the highest level of care, treatment and education.

That's where the BCDI Blood DROP Society will play a crucial role! Members of this honored group will provide financial support for vital services that benefit the bleeding and clotting disorders community throughout downstate Illinois. All contributions to the BCDI Blood DROP Society benefit the BCDI Foundation, including expanding comprehensive care outside of our clinic walls, scholarship programs, continuing education for BCDI patients and staff members, support of BCDI research, emergency financial assistance, and many other initiatives that impact the lives of those we serve.

DROP is an acronym that has a major impact on the mission of this new fundraising group:

Donors Recognizing Our Purpose.

To join the BCDI Blood DROP Society, individuals, groups or organizations must raise or donate a minimum of \$1,000 within a calendar year. There are three different levels of support to join the BCDI Blood DROP Society, with various financial categories ranging from a one-time giving of \$1,000, ranging up to lifetime memberships. To view the various levels of the BCDI Blood DROP Society, please scan the QR code above or visit ilbcdi.org/get-involved/blood-drop-society.



As a BCDI Blood DROP Society member, you will receive name recognition for one calendar year on our new BCDI Donor Wall. This beautiful piece of art has been unveiled in our BCDI patient lobby and is sure to be an eye-catching and spectacular addition to our facility.

BCDI Blood DROP Society members will also receive name recognition in every addition of the BCDI Beacon quarterly newsletter, will have exclusive opportunities throughout the year to network with BCDI providers and staff, will receive exclusive BCDI Foundation merchandise and much more!

These generous gifts directly benefit the mission of BCDI and help improve and expand patient services to support our community physically, emotionally and psychosocially. If you are interested in learning more about the BCDI Blood DROP Society, please contact **Jamie Cunningham** at **309-692-5337 (extension 188)** or by email at jamie@ilbcdi.org.

IN APPRECIATION

Lifetime Impact Members:

- In Honor of Deveraux Hubbard II
- The Dills Family Foundation
- Green Chevrolet & The Green Family
- In Memory of Jim Tarantino - The Jim Tarantino Family
- Julie & Dr. Michael Tarantino
- Novo Nordisk Inc.
- Sanofi

Champion Member:

- CSL Behring

Annual Members:

- A Perfect Promotion
- Becky & John Burns
- Bleeding Disorders of the Heartland
- Brian & Lois Marsel
- Denise & Lance Piper
- Dr. Jonathan & Laura Roberts
- Erynn Dykstra
- Illinois CancerCare
- John & Nancy Machens
- Kollet & John Barkhouse
- Kristen & Bob Manning
- Michael & Sheila Hawes
- PIP Marketing, Signs, & Print
- Sandra Fafoglia

BEACON OUTREACH

EDUCATIONAL DINNER WITH DR. ROBERTS

Throughout the year, BCDI aims to provide education to the general public throughout the state to share crucial information about signs and symptoms of the conditions we treat. The BCDI team, alongside community partners Bleeding Disorders of the Heartland and Bleeding Disorders Alliance Illinois, hosted an educational dinner in Moline on September 30 at The River House restaurant.

With over 40 guests in attendance from the Quad Cities area, BCDI Associate Medical and Research Director Dr. Jonathan Roberts presented an educational discussion entitled "Optimizing Outcomes Beyond Treatment: The Value of Comprehensive Care for Individuals with Bleeding Disorders."

In this interactive presentation, Dr. Roberts explained that living with a bleeding disorder requires lifestyle changes that not only affects the individual with the diagnosis, but their loved ones as well. That's why Hemophilia Treatment Centers, like BCDI, utilize a comprehensive care model that addresses whole patient care. BCDI has a long-term track record of providing timely diagnosis, treatment plans and optimal outcomes for persons with bleeding disorders.



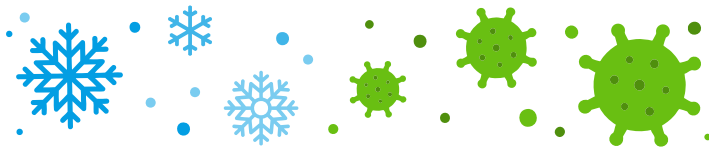
Would you be interested in having an educational dinner in your city to help raise awareness about bleeding and clotting disorders? We would love to accommodate you and host a similar event for your community!

If interested, please reach out to BCDI's Director of Outreach & Communications, Matt McClain, by phone at 309-692-5337 (ext. 140) or via email at mattmm@ilbcdi.org.



BEACON SUPPORT

STAYING HEALTHY THROUGH THE WINTER



As colder months rapidly approach, it is important for individuals with bleeding, blood clotting or other blood disorders to take precautions to decrease your chances of getting sick throughout the season.

Be proactive with preventative care. Flu season starts in early October and can last until May. A flu shot not only prevents serious health complications from the seasonal flu, but it can also lessen the severity of the illness should you become sick. Additionally, it's important to schedule yearly physicals for your entire family. An annual preventative health exam with your primary care provider is the best way to monitor any current health conditions, discuss any new concerns and ensure you're taking the best care of your body.

Get consistent sleep. When days get busy and our to do lists get lengthy, we typically sacrifice sleep. Since sleep affects both physical and mental health, we can't function at our best when we are tired. You may think of the direct relationship between rest and our moods, but frequent lack of sleep raises the risk of many diseases including heart disease, obesity and dementia. Take steps to make sure you regularly get a good night's sleep by establishing a regular bedtime and wake up time. Keeping a dark, quiet sleep environment and limiting the use of electronics before bed can also help your mind and body to wind down. If you are having trouble getting to sleep, it can be helpful to look at your daytime routine. Make sure to limit stimulants like caffeine later in the day and avoid large meals and alcohol in the evening. Getting at least 30 minutes of natural sunlight each day and including physical activity as part of your daily routine can help to promote more restful sleep.

Aim for a healthy lifestyle. Establishing healthy habits can be your first line of natural defense in fighting off illness this winter. To keep your immune system working properly, there are several steps you can take throughout the day to protect yourself. Maintaining a diet high in fruits, vegetables and healthy fats from nuts and fish will help boost your immune system. Prior to eating or preparing food, make sure to wash your hands for at least 20 seconds. Consuming alcohol in moderation and avoiding contact with cigarette smoke will also support a healthy immune system. Although the winter is notorious for busy months filled with holiday events, aim to keep your stress low and set aside time to relax and recharge.

Maintain a healthy weight. Keeping off weight during the holiday season can be difficult with all the socializing, parties and favorite seasonal treats. Weight gain occurs when you take in more calories than your body needs. The NIH Body Weight Planner is a tool that can help you calculate exactly how many calories you need for your weight loss goals. To lose weight, a good rule of thumb is to eat 500 fewer calories than you burn per day. This yields a loss of about one pound per week. You can trim excess calories by limiting less healthy foods that are high in saturated fats, refined carbohydrates or sugar. Focus on eating a majority of nutrient-rich foods like whole grains, lean meats, fresh fruits and vegetables, and low-fat dairy products to fuel your body.

Continue to stay active. Not only does physical activity help to burn off the calories you consume, which is often crucial in maintaining a stable weight, but it also helps to relieve stress and promote overall health. The American Heart Association's physical activity recommendations are to get at least 150 minutes of aerobic exercise each week. This becomes more challenging with colder temperatures and unpredictable winter weather. Consider bundling up and walking outside to get some exercise and some sunlight as well. When the weather does not allow for outdoor activities, try online workouts, join a local gym or try a new fitness class. You can also get creative with moving your body by simply doing chores around your home such as vacuuming, reorganizing and then donating unused items to local charities.

BEACON BOTTOM LINE

DR. TARANTINO WINS NBDF LIFETIME ACHIEVEMENT AWARD

At the National Bleeding Disorders Foundation's 76th annual Bleeding Disorders Conference on September 14, 2024 in Atlanta, BCDI CEO/CMO Dr. Michael Tarantino earned the distinguished honor of NBDF's Lifetime Achievement Award.

The NBDF Lifetime Achievement award is given in honor of Dick James, and recognizes an individual who has dedicated their life to the inheritable blood and bleeding disorders community to improve the lives of those affected. The recipient has contributed their time and energy on a national or international scale to advance research, care, and advocacy, and develop new leadership that will lead NBDF into the future. Dick James [1951-1993], who had hemophilia and AIDS, was an advocate and leader on behalf of people with inheritable blood and bleeding disorders and HIV.



Dr. Tarantino earned a medical degree from the University of Wisconsin School of Medicine in 1987, after which he completed a residency in pediatrics at the University of Arizona Health Sciences Center and a fellowship in pediatric hematology/oncology at the University of Wisconsin. He is board certified in pediatric hematology/oncology and has more than 30 years of experience caring for children and adults with blood and/or clotting disorders. Dr. Tarantino began working as a hematologist in Peoria in 1999, and founded the Bleeding & Clotting Disorders Institute in 2010. In the 14+ years of its history, BCDI's staff has helped treat over **8,000 patients** with bleeding, blood clotting or other blood disorders. Dr. Tarantino also serves as Professor of Pediatrics and Medicine at the University of Illinois College of Medicine–Peoria and maintains an academic program of clinical and translational research. He is considered a national and international thought leader in the areas of hemophilia, von Willebrand disease, thrombophilia, primary immune thrombocytopenia (ITP), and other platelet disorders. He has authored or co-authored more than 150 peer-reviewed publications and numerous reviews and book chapters, along with over 160 scientific abstracts.

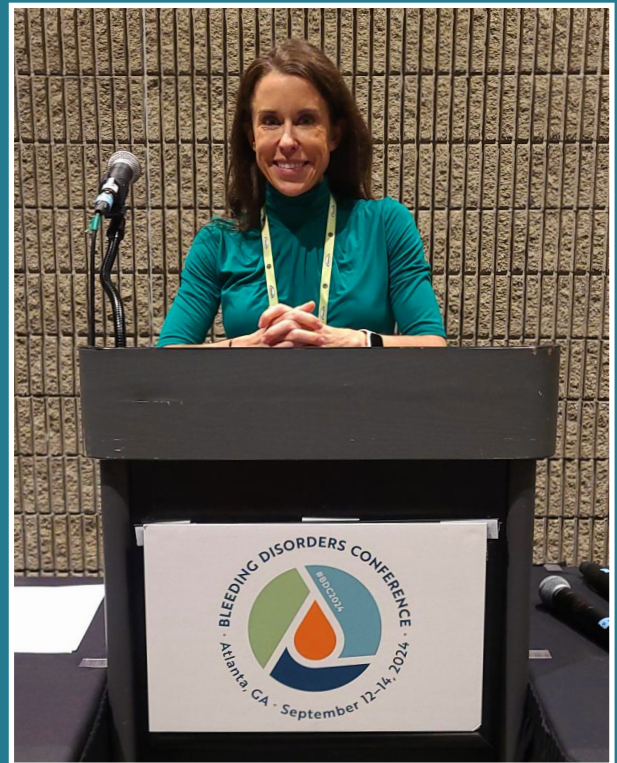


Dr. Tarantino is passionate about advocating on behalf of individuals with bleeding and clotting disorders, and as a result, leads the way for improvements within this community. With NBDF, he served as a member of the Medical Advisory and Scientific Council from 2012 – 2022. In 2012, Dr. Tarantino was awarded the Physician of the Year by NBDF and in 2018 was honored with the Excellence in Healthcare Award by NBDF. Since 2006, Dr. Tarantino has served on the Medical Advisory Board of the Platelet Disorder Support Association (Chairman from July 2021 – July 2024) and is leading the charge to educate members of Congress about promoting a national network of centers of excellence for ITP using an adapted model of comprehensive care based on the first ever ITP comprehensive care clinic in the United States, which was held at BCDI in 2017.

NBDF BDC 2024 REVIEW

The expert staff from the Bleeding & Clotting Disorders Institute helped play a key role in education and advocacy at the National Bleeding Disorders Foundation's 2024 Bleeding Disorders Conference in Atlanta, Georgia, from September 12 – 14.

BCDI Associate Medical/Research Director **Dr. Jonathan Roberts** took part in the Medical and Scientific Advisory Council's (MASAC) meeting. MASAC is composed of physicians, scientists, and other medical professionals with a wide range of expertise on bleeding disorders, blood safety and infectious disease, representatives from government agencies, and people with bleeding disorders. MASAC establishes standard treatment guidelines often referred to by international experts, medical schools, emergency room personnel and many others. Dr. Roberts also unveiled a medical research abstract in the BDC exhibition hall entitled "A Prospective, Observational Study of the Impact of Efanesoctocog Alfa Prophylaxis on Physical Activity and Goal Attainment in Moderate or Severe Hemophilia A." This research focuses on a new hemophilia A treatment and how physical activity will affect their factor VIII levels.



As a part of the physical therapy education track, BCDI registered dietitian **Beth Helmold** provided crucial information to medical professionals in a session entitled "Meeting the Varying Nutritional Needs of Persons with Bleeding Disorders." In this interactive session, Beth encouraged the prioritization of good nutrition as a key component of maintaining good overall health for individuals with a bleeding disorder. Beth provided vital information on how to fuel our bodies with proper nutrients, how to evaluate unique and personal needs, and how to set daily goals and how they can be achieved.



BEACON TIPS

CHOOSING YOUR HEALTH INSURANCE

A GUIDE FOR OPEN ENROLLMENT SEASON

As we enter open enrollment season, it's crucial to understand what to look for when determining which health insurance plan to choose. Selecting a plan involves more than just considering the monthly premium; there's no one-size-fits-all solution. Here's what you need to consider as you evaluate your options.

Premium - The premium is the amount you pay for the privilege of accessing your insurance coverage. Keep in mind that premiums do not count toward your deductible or maximum out-of-pocket expenses. Generally, higher premiums correlate with lower deductibles and out-of-pocket maximums, but this isn't always the case.

Deductible - The deductible is the amount you pay before your insurance carrier begins covering claims. There are two types of deductibles to be aware of:

- Embedded Deductible: Each family member has an individual deductible alongside a family deductible. Once the family reaches the family deductible, the plan starts paying claims for all members, even if an individual hasn't met their own deductible.
- Aggregate Deductible: In this case, there is one deductible for the entire family. No member's claims will be paid until the family deductible is met, but one person can satisfy the entire family deductible.

Maximum Out-of-Pocket - This is the maximum amount you will pay out of pocket for covered healthcare services. Plans typically have separate individual and family maximum out-of-pocket limits. Once you reach this threshold, the health plan will cover all remaining costs.

Coinsurance and Copay - After meeting your deductible, you will be responsible for either copays (set amounts) or coinsurance (a percentage of the total claim). Both copays and coinsurance count toward your maximum out-of-pocket limit.

UNDERSTANDING PHARMACY PROGRAMS

As you review plans, it's also crucial to be aware of pharmacy programs that can affect your total costs:



Accumulator Adjuster Programs - These programs ensure that only the funds you personally pay count toward your deductible and maximum out-of-pocket limits. Under such programs, copay assistance or manufacturer assistance may not count toward your deductible or out-of-pocket maximum.

Copay Maximizer Program - Certain drugs may be considered non-essential health benefits, which means they have a separate deductible and are not subject to the Affordable Care Act's cost-sharing limits. These programs maximize manufacturer assistance dollars while preventing members from having individual cost shares for these drugs. Funds received for non-essential benefits do not contribute to the main deductible or maximum out-of-pocket.

Alternative Funding Programs - Some plans may exclude specific drugs or conditions entirely, requiring patients to rely on manufacturer patient assistance programs. Members are typically assigned a broker to assist with applications for these "free drug" programs.

Navigating Complex Insurance Plans - Insurance plan design continues to grow increasingly complex, with plans employing new strategies to manage healthcare spending. If you have questions about the insurance options available to you, don't hesitate to reach out to our office. We are here to help you navigate these offerings and better understand the coverage available to you.

Choosing the right health insurance plan can significantly impact your financial and physical well-being. By considering premiums, deductibles, maximum out-of-pocket costs, and pharmacy programs, you can make a more informed decision that suits your needs. For assistance in understanding your options, call us at 309-692-5337 or email marsha@ilbcdi.org

BEACON BULLETIN

GOLF OUTING REVIEW

BCDI was pleased to host over 100 attendees for the inaugural BCDI Golf Outing at Mt. Hawley Country Club on August 29, 2024. The only things hotter than the 90-degree weather were the scores on the golf course and the fundraising efforts by our incredible community!

Thanks to the efforts of the bleeding, blood clotting and other blood disorders community, our sponsors, volunteers and the golfers at the 2024 BCDI Golf Outing, over \$15,000 was raised for the BCDI Foundation. All proceeds will help improve BCDI patient program services, including the Green Family Scholarship Fund, which has provided over \$110,000 to BCDI patients since 2011 to further their education.

Congratulations to the team of Ted Ralph, Tate Ralph, Jeff Smith and Kevin Whalen who won the inaugural BCDI Golf Outing with a score of – 15 and a round of 56! While the golf competition was exceptional, all attendees had the opportunity to play on course games and network with the BCDI staff. Games and activities on the course included a Golf Ball cannon, a flippy cup competition, a longest-drive marshmallow game, a bags/cornhole contest, a photo-op with a larger-than-life cardboard cutout of Dr. Tarantino, and a BCDI giveaway prize wheel! Plus, winners were awarded for the Longest Putt, Longest Drive, and Closest to the Pin throughout the round!



We'd like to take the opportunity to thank all our community sponsors who helped make the first BCDI Golf Outing a smashing success! CSL Behring (Executive Sponsor), Green Chevrolet (Hole In One Sponsor), Novo Nordisk (Eagle Sponsor), Heart Technologies (Putting Game Green Sponsor) played a big role in our fundraising, while Genentech, Illinois CancerCare, Bishop Brothers Inc., Kepple, PHD Services and PIP were birdie sponsors! We also appreciate our community sponsors who contributed to the 2024 BCDI Golf Outing, including Jimmy's Bar, Dairy Queen, Dick's Sporting Goods, Bleeding Disorders of the Heartland, Jones Bros. Jewelers, Pottstown Meat and Deli, Marilyn Kohn Realtor, Illini Golf, Office On Main, RC Outfitters and the Pekin Firefighters.



It's not too early to begin thinking about our second annual BCDI Golf Outing, which is tentatively scheduled to take place in August 2025!

Be on the lookout for the official announcement of the 2025 BCDI Golf Outing on our BCDI social media pages!



BEACON SPOTLIGHT

MARY ELIZABETH JAMES, MD

Every quarter, BCDI aims to highlight members of the bleeding and clotting disorders community, including patients, families, BCDI staff members and community partners. Dr. Mary Elizabeth James is a hand and upper extremity surgeon at Great Plains Orthopaedics/OSF Orthopedics in Peoria, Illinois. In a recent interview with our BCDI team, Dr. James explained her experiences of referring patients to BCDI and working alongside the BCDI comprehensive care team to provide cohesive care.

Q: Can you kind of describe your role in your profession and your specialty?

A: I'm a hand and upper extremity surgeon and I specialize in conditions such as traumatic injuries on the upper extremities. A majority of the patients that I work with either come in and they've had an ongoing condition like carpal tunnel syndrome, or they've had an injury like a fracture that needs to be fixed urgently. My encounters with BCDI have been mostly patients that have already been diagnosed with a blood condition or a bleeding disorder and are already being treated by BCDI. I have referred patients to BCDI over the years with suspicions of increased bleeding or a history of bleeding.

Q: What types of signs and symptoms do you see at your practice to warrant a referral to BCDI?

A: I don't have a lot of blood loss in my in my procedures because they're typically small and I use a tourniquet. Occasionally, I'll have someone that has out of proportion bruising or has a history of significant bruising or increased bleeding postoperatively. Teenage girls that may have a heavy period and then have a significant amount of bruising or swelling after routine procedure.



Photo Courtesy of Great Plains Orthopaedics

Q: How do you decide when to refer a patient to BCDI, and how has your experience been collaborating with BCDI's team for patient care?

A: I have a very low threshold for referring. I'm a bone doctor, I don't know the specifics regarding bleeding disorders, so I let the experts at BCDI take care of that. The most impressive thing about BCDI and the way you treat patients is that for me, as a surgeon, when I have a patient that has a bleeding disorder, especially like hemophilia and they need surgery, I don't have to worry about if the patient will need factor. Or when does factor need to be infused? Or how often does factor need to be infused afterwards? It's taken care of by BCDI. There's nothing from my standpoint as a surgeon that I have to worry about. I know that the patient's going to get what they need so I can do my surgery effectively and safely.

Q: What sets BCDI apart from other specialty centers that you work alongside?

A: I know your physicians are easy to talk to, they're very professional, very knowledgeable, and they are well known in the community. That's always refreshing when you have a specialty and those physicians are some of the bigger names in that field and being able to talk to them about your concerns. It's always good for me, as a physician, to know you're getting the right information. Once, I had a young patient that I was treating for a fracture that was non-operational, he just needed a cast. And BCDI was on it. He got factor before they came to see me, I put a cast on, and then he got factor afterwards from BCDI. Talking to his parents, they told me about everything that BCDI was providing for this situation, and it was impressive.

BEACON BRIEFS

BCDI TRIVIA 2025

It's never too early to start planning for the party of the year and this is your invitation to save the date for BCDI's premier event of 2025! The 14th annual BCDI Trivia Night fundraiser will be held on **Friday, April 11, 2025**, at the **Peoria Civic Center Ballroom**. BCDI Trivia Night 2025 is themed "The Great Outdoors" and we would love for you to join us in showcasing your favorite activities to do outside! Whether it's camping, hunting, playing sports, leisure activities or anything in between, Trivia Night 2025 will place an emphasis on spending quality time outdoors.

At the forefront of BCDI Trivia Night is fundraising for a terrific cause, as all proceeds raised will benefit the **BCDI Foundation**. All contributions help BCDI support our patients through activities such as scholarship funds, support of research, continuing education for our patients and staff, emergency financial assistance and other initiatives to improve the lives of our patients and their families.

We invite all trivia experts, novices and fun-seekers to join us this year for one of our best trivia competitions yet! This is a team-based competition, with tables of 10 individuals playing on the same team to see which table can score the most correct answers throughout the night! You can sign up individually, as part of a small group and we will place you with others, or you can register for a full table of ten participants to create your own dream-team trivia squad! Plus, all guests are welcome to enjoy our pre-event happy hour with raffles, play games to win unique prizes, compete in our costume contest, will be served a plated dinner meal, access to BCDI staff members and a full program that highlights what makes BCDI special!

Registration will be opening soon for Trivia Night 2025 attendees and for sponsorships. If you are interested in learning more about "The Great Outdoors" event, please contact **Jamie Cunningham** at **309-692-5337 (ext. 188)** or by email at **jamie@ilbcdi.org**. You can also stay tuned to the BCDI events website found by scanning the QR code.



BCDI ACROSS THE STATE

BCDI has over 7,000 patients across the state of Illinois through our ten different comprehensive care locations. During a comprehensive care visit, a patient sees a variety of expert caregivers. From hematologists to social workers, a nutritionist and everything in between – patients learn to live life to the fullest, regardless of their diagnosis. This united approach leads to a timely diagnosis, comprehensive treatment plans and optimal long-term care of patients with bleeding and clotting disorders.

- **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 Visiting Physician
Office 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** Office of Dr. Gregory Brandt
400 N 9th St – 3rd Floor
Springfield, IL 62701





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