

# THE BCDI BEACON

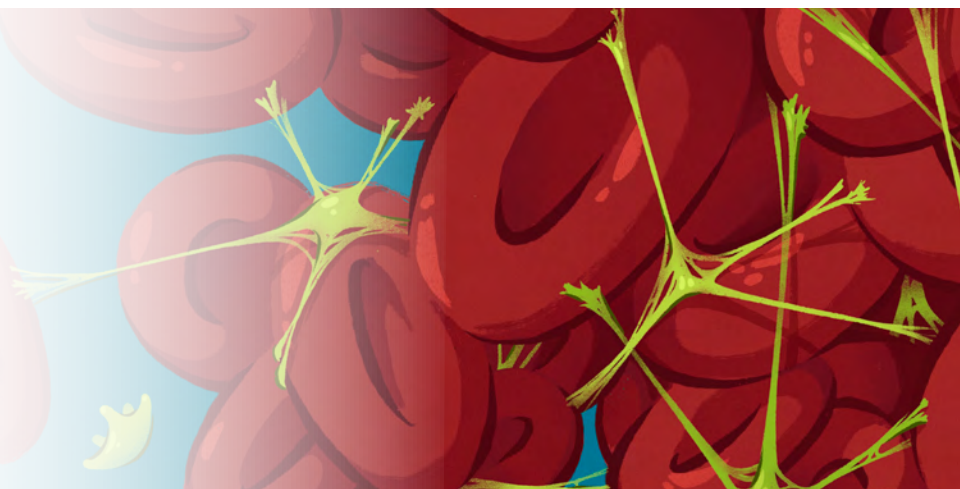
THE BLOOD EXPERTS NEWSLETTER

August 2023 Edition



## FROM HEAD TO TOE

Recapping Our Monumental BCDI Trivia Night Event





## A MESSAGE FROM **DR. TARANTINO**

**Dr. Michael Tarantino**  
**BCDI Chief Executive Officer**  
**BCDI Chief Medical Officer**

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BCDI is extremely excited to introduce our Quarterly Newsletter! BCDI was founded in 2010 and since then, our mission has been to provide integrated, family-oriented care, treatment and education for persons with bleeding, blood clotting and other blood disorders. It is important to understand the comprehensive model that we use to provide excellent health care. This comprehensive model is the center to the clinics that our team holds throughout the entire state at ten different locations- as far north as Rockford and as far south as Carbondale.

Comprehensive care brings a team including a hematologist, nurse practitioner, nurse coordinator, social worker, physical therapist, dietitian and dentist. Each member of the team meets with the patient and then the care team collaborates to create the best care plan for the patient. This care plan is then shared with other doctors the patient sees, as well as the patient and their family. The BCDI pharmacy, research department and laboratory also play a key role in the patient care plan.

The goal of this BCDI Newsletter is to connect with our incredible community and add another layer to our comprehensive care model by providing more information to our patients and families. This newsletter will focus on happenings around BCDI, trends and research in the bleeding and clotting disorders community, important patient information, details regarding events and much more.

I am incredibly proud of the mission that was started over a decade ago, and we hope this newsletter will play a key role in continuing that success into the future. Thank you for your role in supporting and helping in BCDI's success!

## BEACON BUZZ

# BCDI ADVOCACY IN 2023

### **March 8, 2023:** **National Hemophilia Foundation's Washington Days event in Washington D.C.**



BCDI CFO/COO Becky Burns, BCDI Pharmacist Jenna McMechan and BCDI Director of Outreach & Communications Matt McClain spent the day talking to U.S. Congress members about obstacles in our community, federal funding for programs and raising support for policies that increase affordability of coverage and access to care. Offices visited with include Senator Dick Durbin, Representative Darin LaHood, Representative Eric Sorensen, Senator Tammy Duckworth, Representative Mary Miller and Representative Sean Casten.

### **March 22, 2023:** **Illinois Advocacy Day in Springfield, Illinois**

Burns and McClain made a short trip to the Illinois State Capitol to meet with local legislatures to spread the word about Bleeding Disorders Awareness Month. During meetings with Senator Dave Koehler, Representative Ryan Spain, Senator Win Stoller, Senator Sally Turner and Representative Bill Hauter, the BCDI team raised awareness about obstacles that BCDI's Illinois patients are facing regarding access to care and insurance.

### **June 13, 2023:** **Hemophilia Alliance Hill Day event in Washington D.C.**

The BCDI group of Burns, McClain and Pharmacy Manager Dane Christ spoke with members of Congress about the role HTC's play for their patients, the importance of the HTC care model, and raising awareness about the integral part the 340B program plays in providing high-quality care that is offered at HTC's. During this trip, BCDI spoke once again with the offices of Rep. LaHood, Rep. Sorensen and Senator Duckworth, while also holding meetings with staff members from Representative Jan Schakowsky's and Representative Robin Kelly's office.

## BEACON BRIEFS

# BCDI NEWS/EVENTS

## BCDI Family Day- August 27, 2023. Location- Dozer Park, Peoria, IL



Patient education is at the heart of our mission. That's why every year, BCDI provides our patients and their families the opportunity to attend BCDI Family Day event! This event is integral to BCDI's comprehensive care approach, where we help educate persons with bleeding and blood clotting disorders. Family Day 2023 begins with registration for attendees at 9 am, followed by educational workshop sessions presented by BCDI providers. Topics include BCDI's comprehensive care model, new technologies with bleeding disorders, insurance options for healthcare consumers, the BCDI patient wellness program and more! BCDI Family Day was capped off with some minor league baseball, as the Peoria Chiefs played host to West Michigan. During the game, BCDI patients and families were served lunch and had the opportunity to talk with BCDI staff. For more information regarding Family Day, please visit: [www.ilbcdi.org](http://www.ilbcdi.org)

## ITP Awareness Month- September 2023

September is Immune Thrombocytopenia Purpura (ITP) Awareness Month! ITP is a rare bleeding disorder characterized by a low amount of platelets in the blood. Platelets are needed for clotting of the blood.



In patients with ITP, a person's immune system creates antibodies that mark healthy platelets as "foreign substances" and then mistakenly attack and destroy them. As an autoimmune disease that results in the destruction of platelets, patients with ITP tend to bleed or bruise. Worldwide, it is estimated that there are over 200,000 people affected by ITP. Please join BCDI in helping us spread awareness for ITP care and support!

- BCDI will be holding weekly trivia contests on our Facebook page ([facebook.com/ILBCDI](https://facebook.com/ILBCDI)) with winners being awarded BCDI apparel and swag.
- BCDI's patient lobby will be decorated in purple! Purple candy will be provided to patients, a photo opportunity with decorations will be set up and fun games will also be available!
- On September 29, wear your purple clothing for Sport Purple for Platelets Day! The ITP community rallies together on the final Friday of September to don purple gear to raise awareness for ITP and other platelet disorders.
- Be sure to tag your posts to BCDI on social media using the hashtag #ITPatBCDI

## BEACON SPOTLIGHT

Every quarter, BCDI aims to highlight members of the bleeding and clotting disorders community, including patients, families, BCDI staff members and community partners.

### THE KRAEMER FAMILY

Dr. Michael Tarantino has known Ryan and Kristi Kraemer since 2006. On April 28, 2006, the Kraemer's welcomed their first son, Liam, into their lives. Immediately after being born, Liam began showing signs of a bleeding disorder. After further testing, Liam was diagnosed with Severe Hemophilia A with less than 1% clotting factor at just two weeks old. The next couple of months were extremely scary for the Kraemer's with unknowns of this condition. The family was referred to Dr. Tarantino for comprehensive care, and they found hope in their new care team.

"If you think back to when he was born in 2006, it wasn't as easy just to Google things and learn about this condition," Ryan Kraemer said. "So, we didn't have the immediate access to the information that maybe somebody that's diagnosed today would have. So, there was a lot of unknown until we got up and got with Dr. Tarantino."

"Dr. Tarantino sent us home with a lot of books, a lot of posters," Kristi Kraemer said. "It made me realize how lucky and blessed we were through the whole labor and delivery with Liam and how many things could have gone wrong. But as soon as we got with Dr. Tarantino, there was an immediate connection with him. He was so welcoming and just so helpful, and I think he even gave us a cell phone number."

On November 11, 2010, the Kraemer's second son, Kolby, was born and was also diagnosed with Severe Hemophilia A shortly after birth. Flash forward 13 years, and Liam (17 years old) and Kolby (12 years old) say their Hemophilia A condition has become second nature, as they self-infuse factor three times a week. The Kraemer's also have two daughters, Zoey and Drew, who are potential Hemophilia A carriers.

"When you have two daughters that are possibly carriers, this disease can go beyond these two boys that we have," Ryan added. "In the future, patients may not have to go through the pain of getting weekly injections and some of the difficulties that we've had. But now we're over that hurdle and the boys can inject themselves and they live a normal life. But compared to what our grandsons may live one day, it may even be better. So, you need to continue with research and coming up with better, better methods to treat it."

"We feel our boys are living normal lives and we have nothing but gratitude and appreciation for the entire staff at BCDI," Kristi said. "They are like family to us and we appreciate all the work and research they do to provide our boys with the best care, as well as provide information to us as it becomes available. We love Dr. Tarantino and his team!"



## BEACON BOTTOM LINE

# BCDI BOTTOM LINE TRIVIA NIGHT 2023

BCDI held its 12th Annual Trivia Night fundraising event June 2, 2023, at the Four Points by Sheraton Hotel in downtown Peoria. This year's event proved to be one of the best Trivia Night's yet, with over 230 guests in attendance!



Thanks to the tremendous generosity from donations, raffle items and sponsorships, BCDI's fundraising goal was exponentially surpassed! This year's event raised over \$100,000.00 to support the continued mission of BCDI to provide integrated, family-oriented care, treatment and education for individuals with bleeding, blood clotting and other blood disorders.

"Head To Toe" was the theme for Trivia Night 2023, and all attendees were encouraged to wear their favorite hat and shoe combination, which sparked a lot of creativity and amazing outfits! This theme was not only for our guests to have some fun, but also to help support the community. This year, BCDI offered table centerpiece sponsorships to our community members. Each \$50 centerpiece sponsorship not only paid to decorate our tables, but the shoes acquired as part of the centerpieces were purchased with the intent to pay it forward and continue to support the Peoria area.

With that generosity in mind, BCDI took 25 pairs of shoes and donated them to Threads Hope & Love- a nonprofit, charitable organization located in Washington, Illinois, that serves surrounding communities. Threads, Hope & Love serves nearly 3,800 families in central Illinois, providing ones in need access to clothing, linens, small household and other items.





At our pre-function event, guests were able to buy tickets to our amazing Beer and Wine Pull, a sock gift-card pull, raffle tickets for six incredible raffle baskets and pay for a chance to win their very own Pop-A-Shot basketball game! The incredible Katie Belle and Dufflebag Joe performed live-music during the pre-function event for one hour, providing energy to the event through their earthy roots rock music.

During the event, we presented this year's BCDI Hero Award to Congressman Darin LaHood, who serves the constituents of the 16th District of Illinois with the United States House of Representatives. Congressman LaHood has been instrumental in introducing and passing legislation that helps those with a bleeding disorder access affordable treatments, including through the introduction of the Hemophilia SNF Access Act in 2020. This act opened care from skilled nursing facilities up to patients with hemophilia who would have been otherwise turned away from these care providers due to the cost of their medication.

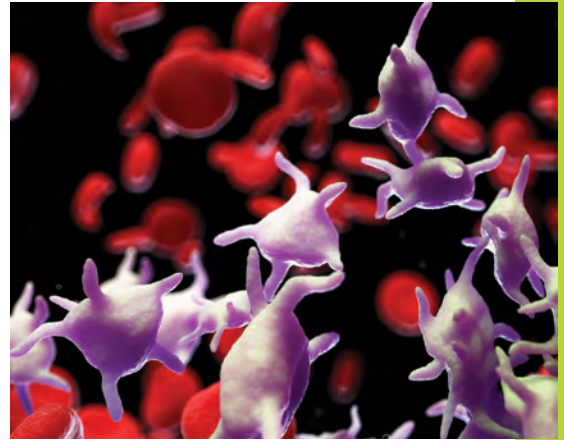
With that being said- we are already thinking about **Trivia Night 2024** and we would like to give you a sneak peek at some details! The theme of our **13th Annual BCDI Trivia Night** will be **24 Karat Gold**- to embrace the year **2024**! Our tentative date for **Trivia Night 2024** is **Friday, April 19, 2024**, and we are still finalizing details on the location of the event. **Stay tuned for more information!**



## BEACON TIPS

# LIVING WITH ITP

With Immune Thrombocytopenia Purpura (ITP) Awareness Month right around the corner in September, the BCDI team has some steps you can take to help minimize some of the most common challenges ITP presents and help improve your overall quality of life.



ITP is a bleeding disorder characterized by a low amount of platelets in the blood. Platelets are needed for proper clotting of the blood. In patients with ITP, their immune system creates antibodies that mark healthy platelets as “foreign substances” and then mistakenly attack and destroy them. As an autoimmune disease that results in the destruction of platelets, patients with ITP tend to bleed or bruise easily.

When you have ITP, feeling better is often the result of many small lifestyle changes that can lead to a major improvement. Here are some tips for staying on top of your overall health, especially for persons with ITP:

- Many people with autoimmune diseases, like ITP, feel tired and tend to have low energy. There are several reasons why those with ITP may experience fatigue, including iron deficiency. Ways you can boost your overall energy include:
  - Aim to make your diet a majority healthy foods: lean protein, whole grain carbohydrates, low fat dairy products, fruits and vegetables.
  - Limit the portion sizes and frequency of desserts, salty snacks, sugary drinks and fast food.
  - Drink plenty of water, which may need to be increased after exercise, during illness or with hot weather.
  - Rest your body by getting at least seven hours of sleep at night.
- Uncontrolled bleeding is a possibility with ITP. Being prepared for a spontaneous bleed is one of the most imperative steps you can take to help reduce bleeds.
  - Carry medications to help prevent and reduce bleeds.
  - Keep a nosebleed treatment kit on hand. During your next visit to BCDI, ask your nurse for a nosebleed awareness kit, which includes hypertonic saline spray, adhesive bandages, a nose clamp and an informational nosebleed magnet.
- Overall health tips include, but not limited to:
  - Reduce Stress.
  - Exercise- good examples would be swimming, stationary cycling or yoga.
  - Avoid medications that can interfere with platelets function.





## 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
- **Springfield** Springfield Clinic at St. John's Pavilion Dr. Brandt's  
Office 301 N 8th St – 4th Floor Springfield, IL 62701
- **Women's Services Clinics:** Bleeding & Clotting Disorders Institute  
427 W Northmoor Dr. Peoria, IL 61614
- **Thrombophilia Clinics:** Bleeding & Clotting Disorders Institute  
427 W Northmoor Dr. Peoria, IL 61614
- **Immune Thrombocytopenic Purpura (ITP) Clinics:** Bleeding & Clotting Disorders Institute  
427 W Northmoor Dr. Peoria, IL 61614





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[www.ilbcdi.org/about-us/newsletter](http://www.ilbcdi.org/about-us/newsletter)



## GET IN TOUCH



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