

THE BCDI BEACON

THE BLOOD EXPERTS NEWSLETTER

August 2024 Edition



FAMILY DAY FUN

BCDI's 2024 Family Day Made a Splash!



A MESSAGE FROM **DR. TARANTINO**

BCDI Chief Executive Officer
BCDI Chief Medical Officer



TABLE OF CONTENTS

- Beacon Education: Moline Outreach Event, **Page 3**

- Beacon Outreach: PDSA ITP Conference 2024, **Page 4**

- 2024 BCDI Golf Outing, **Page 5**

- Beacon Bottom Line: BCDI Family Day, **Pages 6 & 7**

- Beacon Spotlight: Simon Francis, **Page 8**

- Beacon Bulletin: BCDI Blood Drop Society, **Page 9**

- Beacon Tips: Physical Therapy at BCDI, **Page 10**

- Beacon Briefs: Cyd's in the Park, **Page 11**

The entire team at the Bleeding & Clotting Disorders Institute is committed to providing the highest quality of care to bleeding, blood clotting and other blood disorders patients and their families. In the first seven months of 2024, BCDI has hosted 57 different comprehensive care clinics spanning over 10 different cities in Illinois. This level of commitment remains top priority, and this edition of The BCDI Beacon Newsletter will help shed light on some of our newest campaigns.

This summer at BCDI, we have taken strides to improve the way we provide education to our community about bleeding and blood clotting disorders. In July, BCDI hosted our annual Family Day event where patients and family members joined the expert BCDI staff for a day of education, carnival fun and games, and food. Over 80 participants came to the BCDI campus in Peoria and for the first time ever, the education portion of Family Day was live streamed to our community and will also be made available to our patients.

BCDI is also excited to share information about an upcoming educational dinner in Moline and is free to attend. On Monday, September 30, 2024, BCDI will present a talk about optimizing patient outcomes beyond treatment in the bleeding disorders community. By the end of 2024, BCDI will also introduce a continuing education platform where BCDI will partner with healthcare providers throughout Illinois to ensure optimal outcomes for individuals with bleeding and blood clotting conditions.

Alongside the efforts to increase the education and awareness provided about bleeding and clotting disorders, BCDI is also excited for the upcoming inaugural BCDI Golf Outing Fundraiser. The 2024 BCDI Golf Outing will take place August 29 in Peoria, with all proceeds benefiting the BCDI Foundation to improve patient program services offered at BCDI. Any contributions from the BCDI Golf Outing will help provide top quality care to our patients, while strengthening our vision of what is possible in the future.

More than ever, BCDI is dedicated to providing the highest level of comprehensive care possible, and we are always looking for ways to improve our services. Thanks to your continued support, our team looks forward to strengthening our incredible relationships as BCDI provides a beacon of hope by being a driving force in advancements within the bleeding and clotting disorders community.

BEACON EDUCATION

MOLINE OUTREACH EVENT

The Bleeding & Clotting Disorders Institute consistently delivers the highest standard of care and education to individuals with bleeding disorders, blood clotting, and other blood related disorders. Alongside Bleeding Disorders of the Heartland and the Bleeding Disorders Alliance Illinois, BCDI is hosting a **FREE** educational dinner event in Moline, Illinois on Monday, September 30, 2024 at River House (1510 River Dr, Moline IL 61265) from 6:00 p.m. – 7:30 p.m.

BCDI Associate Medical/Research Director Dr. Jonathan Roberts will be the keynote speaker during the event, leading a presentation entitled "Optimizing Outcomes Beyond Treatment: The Value of Comprehensive Care for Individuals with Bleeding Disorders." In this interactive presentation, Dr. Roberts will explain the importance of expert care at comprehensive care clinics, which have a long-term track record of providing timely diagnosis, treatment plans and optimal outcomes for persons with bleeding disorders.

Living with a bleeding disorder requires lifestyle changes that not only affect the individual with the diagnosis, but their loved ones as well. That's why Hemophilia Treatment Centers, like BCDI, utilize a comprehensive care model. This multi-disciplinary approach addresses whole patient care, including physical, mental and emotional concerns impacted by a diagnosis.

This educational dinner event is free for BCDI patients to attend, but you must register to attend as space is limited. If you would like to register to attend, please visit the event website by scanning the QR code or by visiting:

<https://lp.constantcontactpages.com/ev/reg/2w7czmk>.

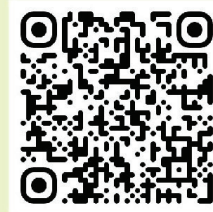
FREE

EDUCATIONAL DINNER

JOIN BDH, BCDI, & BDAI

SEPTEMBER 30 • 6-7:30PM

THE RIVER HOUSE
1510 RIVER DR, MOLINE IL



REGISTER NOW



BEACON OUTREACH

PDSA ITP CONFERENCE 2024

BCDI's team of esteemed experts represented the bleeding and clotting disorders community at the Platelet Disorder Support Association's 24th Annual ITP Conference in San Antonio, Texas on July 26 – 28. This event continues to be a vital platform for individuals and families impacted by ITP (immune thrombocytopenic purpura), which is a rare bleeding disorder characterized by a low amount of platelets in the blood.

BCDI Chief Executive Officer and Chief Medical Officer Dr. Michael Tarantino serves on the PDSA Board of Medical Advisors and played a key role in the success of PDSA's 2024 ITP Conference. Dr. Tarantino led a question-and-answer session about ITP in Adults and the Evolution of ITP treatment and guidelines, as he shared the best practices when it comes to the use of steroids for individuals with an ITP diagnosis. Dr. Tarantino also led a keynote dinner program entitled "Taking Charge of Your ITP Journey Together With Your Doctor," which placed an emphasis on the important conversations that patients need to have with their hematologist and how to empower patients to become their own advocate.

BCDI Chief Operating Officer and Chief Financial Officer Becky Burns led a presentation entitled "Financial Toxicity: Navigating Insurance with a Rare Disease." In this interactive session, Burns provided key information to ITP patients and families about important insurance terms to know, highlighted challenges that prior authorizations and coverage denials pose, and helped define consequences of high patient cost-share, copay assistance and coinsurance.

PDSA's ITP Conference also provided a teen education track, where BCDI Advanced Practice Provider Supervisor Kristin Ansteatt and BCDI Nurse Coordinator Kelsey Kuhel joined Dr. Tarantino in leading the teen sessions. Each year, the BCDI team creates a project that allows teens to share about their ITP diagnosis and discuss their journey with others. This year, a mascot and tagline were created for the teens group based off drawings about their experiences with ITP. BCDI graphic designer Sophie Tarantino then re-created the drawings to be printed out as stickers, with a plan to make sticker packs out of the projects completed at the last three years of the PDSA ITP Conference.

With over 250 guests in attendance at PDSA's 2024 ITP Conference, the BCDI team made a large impact in sharing vital education to individuals with an ITP diagnosis. We invite you to join us during the month of September for ITP Awareness Month, where BCDI will help spread crucial information about living with ITP, how to minimize some of the most common challenges ITP presents and to help improve your overall quality of life.



2024 BCDI GOLF OUTING



Are you ready to tee it up for a fun day of golf and to help raise awareness and funds for the bleeding and clotting disorders community? The inaugural BCDI Golf Outing will be held on **Thursday, August 29, 2024**, at **Mt. Hawley Country Club** in Peoria, Illinois with a **10 AM start time!**

The first-ever BCDI Golf Outing is a charity event and will help raise crucial funds for a good cause! All proceeds raised at the BCDI Golf Outing will benefit the BCDI Foundation, including improvements to patient program services and the Green Family Scholarship Fund, which provides financial assistance to BCDI patients to further their education.

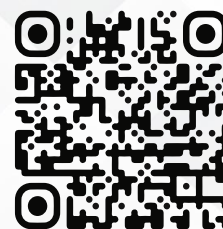
Registration is still open to sign up to play in the BCDI Golf Outing, but space is limited! Pricing for a group foursome of golfers is **\$600**, or you may register as an individual for **\$150**. Alongside an exciting day of golf at one of central Illinois' premier golf courses at Mt. Hawley Country Club, each golfer will also get access to raffle baskets, contests and prizes during the round of golf, a post-round award ceremony with prizes and heavy hors d'oeuvres, plus opportunities to network with BCDI staff members!

Not a golfer but still want to support BCDI's mission? You can join us for our post-golf Happy Hour! Beginning at 3 p.m. and running through 4 p.m., guests can enjoy heavy hors d'oeuvres and drinks from the bar. Guests will also be able to purchase tickets for our premium BCDI Golf Outing raffle baskets, buy 50-50 tickets and attend the BCDI Golf Outing award presentation beginning at 4 p.m.

The 2024 BCDI Golf Outing will begin on August 29 with a 10 a.m. shotgun start. Lunch will be provided to all golfers during the round. The BCDI Golf Outing will be a four-person scramble format. Golfers will play the 18-hole round in a team of four players, where each member hits their own golf ball throughout the round. For each stroke, the team selects the "best shot" from the group and each member of the team hits their own ball from that spot. This process continues until all holes are completed. There will be a two-putt maximum at each hole. There will be a number of fun games and giveaways throughout the course, including a chance to win a BRAND NEW CAR courtesy of our friends at Green Chevrolet!

Sponsorship opportunities are still available for the inaugural BCDI Golf Outing. If you are interested in learning more about the various sponsorship opportunities, please contact **Jim Rea** by email at jim@ilbcdi.org or call **309-692-5337**.

For more information about the BCDI Golf Outing and to register to play, please scan the QR code or visit bcdigolf.cbo.io.



BEACON BOTTOM LINE

BCDI FAMILY DAY

We are thrilled to share the highlights from our recent Family Day event, which brought together our BCDI community in a spirit of carnival fun and learning.

The day kicked off with a warm welcome from Dr. Tarantino, followed by a delicious lunch from **Brian Barron BBQ** and **Hy-Vee Grill**, making sure everyone was well-fed and ready for the day's events. Our expert BCDI staff led specialized educational sessions, offering valuable insights for both parents and teens. These sessions were facilitated by Dr. Tarantino, Dr. Roberts, Becky Burns, and Beth Hemold.



While the adults and teens were immersed in learning, the younger attendees enjoyed carnival games and activities designed for all ages. **Fun on the Run** provided an array of carnival attractions, while **Barnyard Discoveries** brought an educational petting zoo featuring adorable farm animals. Guests also indulged their sweet tooth with treats from **Kona Ice of Peoria** and **Kamaela's Creamery**.



The carnival spirit was alive with face painting, a balloon artist, and exciting games organized by our dedicated BCDI team. One of the event's highlights was the dunk tank starring Dr. Tarantino and Dr. Roberts. Patients and staff eagerly participated, resulting in plenty of laughter and splashes!

We would like to thank all the BCDI staff, patients, and families who contributed to making this event a tremendous success. Your participation and enthusiasm truly embody the spirit of our community, and we look forward to seeing everyone again at future events! Thank you to **A-Tay Photography** for capturing the many fun-filled moments! Visit our facebook page to see more photos of the festivities.



BEACON SPOTLIGHT

SIMON FRANCIS

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

Simon Francis was born June 29, 2018, and within his first week of life was diagnosed with Hemophilia A. The journey through Simon's diagnosis and first year of life was a rollercoaster of emotions for parents Scott Francis and Rebecca Francis.

"Imagine the stereotypical new parents wide eyed and trying to process an already hectic time of birth and fatigue. Now add an unknown and medically complex diagnosis of your son having Hemophilia A." Rebecca Francis said. "Being told that your newborn baby will be transported via a very expensive and very special ambulance that requires special staff and very small equipment."

Shortly after Simon's diagnosis, the Francis family met BCDI hematologist Dr. Jonathan Roberts during a local hospital rotation. To this day, Simon is still a patient of Dr. Roberts.

"Dr. Roberts continues to set the bar for excellent patient care," Rebecca said. "When we first met Dr. Roberts, he spoke about how there is a patient care staff meeting every Tuesday, and Simon was the center of their attention. He also shared stories from his childhood (Dr. Roberts has severe Hemophilia A) and continued to reinforce the narrative that Hemophilia was not to be feared."

Before Simon's first birthday, the Francis family had several scares where emergency medical attention was required. In separate incidents, Dr. Roberts provided on-call support, BCDI registered nurse Missy Quin assisted with a soft tissue bleed and BCDI COO/CFO Becky Burns helped with complex barriers to insurance coverage on more than one occasion.



The Francis family is also involved in advocacy and raising awareness for individuals with bleeding disorders. Rebecca is a member of the Patient Advisory Board at BCDI, which is a patient-led group which provides guidance and feedback on how the care team at BCDI can continue to meet the best standards of comprehensive and compassionate healthcare. The Patient Advisory Board provides BCDI patients an opportunity to come together and share ideas that may benefit the bleeding disorders community.

"As a mother of a patient, I am committed to this cause and the clinic," Rebecca added. "It is very important to me as a member of the Patient Advisory Board to further the success of the clinic for the betterment of their patients from all ages and walks of life. Dr. Tarantino has built up an excellent team who continues to research, advocate and move BCDI into the forefront of this field."

BEACON BULLETIN

BCDI BLOOD DROP SOCIETY



At BCDI, we rely on the philanthropic support of our community and donors to help us fulfill our integral mission of providing integrated, family-oriented care, treatment and education for individuals with bleeding, clotting and other blood related disorders. With that in mind, BCDI has created a brand-new donor society for our community: The BCDI Blood DROP Society. DROP serves as an acronym that greatly impacts the mission of this new fundraising group: Donors Recognizing Our Purpose.

Members of this honored group will support vital services that will benefit the entire bleeding and clotting disorder community throughout Illinois, every day, thanks to their generous contributions. Those who donate or raise \$1,000 or more within a calendar year for BCDI are acknowledged as members of the BCDI Blood DROP Society and will also receive name recognition for at least one calendar year on our new BCDI Donor Wall. This beautiful piece of art is set to be unveiled in our BCDI patient lobby in 2024 and is sure to be an eye-catching and spectacular addition to our facility. There are various levels of becoming a BCDI Blood DROP Society Member and each have different perks that play a key role in membership.

ANNUAL MEMBER: \$1,000 +

- 1-year recognition on the Blood DROP Society Donor Wall (small size).
- Welcome kit including BCDI swag, information and the BCDI Beacon Newsletter.
- VIP Invite to special BCDI events.
- Invitation to Annual BCDI Blood DROP Society Appreciation Event.
- Special merchandise availability, tour of BCDI facility, and more!

CHAMPION MEMBER: \$5,000 +

- 1-year recognition on the Blood DROP Society Donor Wall (medium size).
- Preferred seating at BCDI events.
- All benefits of Annual Member Level.

LIFETIME IMPACT MEMBER: A ONE-TIME DONATION OF \$10,000 +

- Lifetime Recognition on the Blood DROP Society Donor Wall (large size).
- Lifetime membership to the donor society.
- All benefits of Champion and Annual Member Levels.

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're interested in learning more about the BCDI Blood DROP Society, please contact **Matt McClain** at **309-692-5337 (extension 140)** or by email at **mattmm@ilbcdi.org**

BEACON TIPS

PHYSICAL THERAPY AT BCDI

BCDI is committed to providing excellent patient care. Comprehensive Care Clinics are one of the many ways we work to achieve this goal. Use of a multidisciplinary team helps us deliver care that focuses on different aspects of the individual to provide the best patient-centered experience. Physical Therapy is an important component of our Comprehensive Team.

Physical therapists provide interventions that target improving areas such as range of motion, flexibility, balance and strength. An advancement in these areas can help improve pain levels including chronic pain, mobility during daily tasks and encourage safe participation.

Pain whether short lived, chronic, or injury provoked can cause a disruption in our daily routine. Physical therapists work with you to decrease pain levels through interventions such as strengthening, stretching, guided progression of exercises, manual hands-on techniques and more.

When pain, a recent bleed or other factors decrease participation, physical therapists will work with you to help modify activities allowing return to full performance. At times, this may require assistive devices such as canes/walkers/crutches. Your physical therapist can help you learn how to navigate the use of these devices and adjust them to your correct height. Other modifications may include changing an office desk set up to prevent neck pain or providing training in lifting techniques to decrease strain on your back. We may discuss proper fitting gear or footwear when performing sports, recreation or prolonged walking. For our younger population, we work to make sure they are hitting their target developmental milestones needed for play and keeping up with their friends.

Safety with activities is another goal that physical therapists aim to work on. We work with patients and the comprehensive care team to help assist with choosing safe exercise/sporting options. Other concerns for safety include falling and loss of balance. Physical therapists can offer ideas on modifications to home environment, exercises for strengthening and exercises to improve balance such as our body's awareness of where we are in space.

We know that many bleeding and clotting disorders affect multiple aspects of one's life and well-being. During comprehensive care visits we educate on joint health, activity choices, and continue to monitor range of motion, strength, gait, and balance. We are also available to provide education on assistive devices when recovering from bleeds or progression back to activity and range of motion after bleeds/injuries.

Our physical therapist at BCDI, Rachel, wants to work with YOU to help restore function and return to the activities YOU want and love to do! If you have any questions, please contact your care team at BCDI.

WAYS WE CAN ASSIST YOU

- Pain: joint pain, muscle pain, chronic pain
- Range of motion, flexibility
- Mobility: getting in and out of bed, in/out of cars, etc



- Activity modification: helping to make activities safe and increase participation
- Assist with balance
- Assistive device usage and options
- Rehabilitation after injuries



- Developmental Milestones – age appropriate skills
- Postures/positions: lifting techniques, positions for desk work
- Education such as: importance of properly fitting gear/shoe wear and physical activity for overall wellness

BEACON BRIEFS

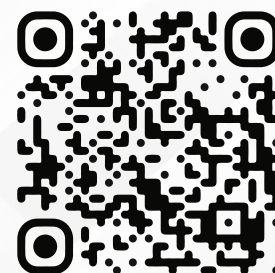
CYD'S IN THE PARK

Are you looking for a great lunch spot near BCDI that is quick and easy? During the month of August, Cyd's in the Park is helping raise money for BCDI!

Located directly across from the BCDI campus in Donovan Park, Cyd's in the Park (5805 Knoxville Ave, Peoria, IL 61614) will be taking all tips from its Take-Away Market and will be donate the funds raised to BCDI as a part of the Cyd's Crew Charity Donation.

The Take-Away Market is on the lower level of Cyd's in the Park with a tranquil, self-service patio with endless views of Donovan Park. Cyd's Take-Away Market has an impressive variety of items available at your convenience, including freshly prepared salads, soups, sandwiches, full entrees and desserts/pastries from Cyd's bakery.

To visit the full menu and to learn more about Cyd's in the Park, please scan the QR code or visit <https://www.cyds.biz/take-away-market/>. Be sure to visit Cyd's Take-Away Market during August!



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





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Monday - Friday



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www.ilbcdi.org/about-us/newsletter

