

THE BCDI BEACON

THE BLOOD EXPERTS NEWSLETTER

November 2023 Edition





A MESSAGE FROM **DR. TARANTINO**

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

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As we approach the end of 2023 and another tremendous year of providing integrated, family-oriented care, treatment and education for our BCDI patients and family members with bleeding, blood clotting or other blood disorders, we would like to thank a moment to thank all of you for your continued support to BCDI. The goal of this newsletter is to connect with our incredible BCDI support system and community, while adding another layer to our comprehensive care model by providing more information and education to our patients and families.

In this edition, you will find various updates on exciting developments around BCDI. One of the most exciting things at BCDI in the last several months is the new "Stop The Clot" Legislation that has been introduced to the Illinois House of Representatives. House Bill 4172 is an important piece of legislation that, if passed, will highlight the challenges and treatment for individuals impacted by blood disorders and will aim to reduce the mortality rate of these disorders across Illinois. We are thankful for Representative Jehan Gordon-Booth for introducing this legislation, and we are grateful for the support and inclusion from the Deveraux Hubbard II Foundation- who has played a key role in advocating for awareness towards blood clots across central Illinois for nearly a decade.

Also in this volume of the BCDI Beacon is brand new information on an exciting campaign launching for our BCDI Blood DROP Society, which aims to improve patient program services at BCDI to support our community physically, emotionally and psychosocially. This donor society will include memberships that are philanthropic in nature that will provide crucial funds to benefit BCDI's mission, but members will also gain exclusive and unique opportunities with BCDI throughout the year!

We are extremely excited about the happenings and developments at BCDI. Thanks to your help and support, this has been one of the best years at BCDI yet. We look forward to continuing our incredible relationships with our BCDI patients and families into 2024 and beyond!

BEACON BUZZ

THE BCDI BLOOD DROP SOCIETY

At the Bleeding and Clotting Disorders Institute, we rely on the philanthropy of our community donors to fulfill our vital mission of providing integrated, family-oriented care, treatment and education for individuals with bleeding, clotting and other blood disorders.

For this reason, BCDI is excited to announce the launch of a brand-new donor society for our community: The BCDI Blood DROP Society. Members of this honored group will support vital services that will benefit the entire bleeding and clotting disorder community throughout downstate Illinois, every day, thanks to their generous contributions.

“Since starting BCDI in 2010, we have grown from serving hundreds to now thousands of patients and families that benefit from comprehensive care and patient services,” BCDI Chief Executive and Medical Officer Dr. Michael Tarantino said. “The BCDI Blood DROP Society will greatly contribute to the much-needed resources required to fulfill our mission.”

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 a lifetime membership. Specific information regarding the different levels will be forthcoming.

While the BCDI Blood DROP Society is philanthropic in nature and will provide crucial funds that will help BCDI’s mission, members of this group will also receive exclusive and unique opportunities and incentives throughout the year.

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 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. BCDI Blood DROP Society members will also receive name recognition in every edition of the BCDI Beacon quarterly newsletter, will be invited to an annual BCDI Blood DROP Society appreciation banquet and will have exclusive opportunities throughout the year to attend other exciting events with BCDI providers and staff.

“BCDI’s legacy of service in many ways depends on the kind generosity of our friends and partners,” Dr. Tarantino said. “Your support of the BCDI Blood DROP Society will also help us expand our services to many patients and families in our underserved communities across downstate Illinois.”

These generous gifts directly benefit the mission of BCDI and help improve and expand patient services to support our community physically, emotionally and psychosocially. To learn more about the BCDI Blood DROP Society and to become a member, please scan the QR code or send an email to matt@ilbcdi.org.



BEACON OUTREACH

BCDI AT NBDF BLEEDING DISORDERS CONFERENCE

Members of BCDI expert staff spent August 17-19 at the National Bleeding Disorders Foundation's Bleeding Disorders Conference in National Harbor, Maryland. At the NBDF's (formerly known as the National Hemophilia Foundation or NHF) Bleeding Disorders Conference, BCDI staff members hosted educational sessions for persons with bleeding disorders and medical professionals, while also attending learning workshops to discuss important topics in our community.

BCDI Associate Medical Director/Associate Research Director Dr. Jonathan Roberts presented a talk entitled "Managing Patients Who Are Living With von Willebrand Disease." This session took a detailed look at a VWD case-based experience, including reviewing treatment history and discussing options that may be added to a treatment plan for prophylaxis. Dr. Roberts also took part in the Medical and Scientific Advisory Council (MASAC) meeting, which is composed of physicians, scientists, and other medical professionals with a wide range of expertise on bleeding disorders, blood safety and infectious disease. MASAC establishes standard treatment guidelines often referred to by international experts, medical schools, emergency room personnel, insurance companies and many others.



BCDI registered dietitian Beth Helmold helped lead a session entitled "Your Health, Your Way: Personalizing Wellness for Women." During the talk, Beth encouraged attendees to build a personal health and wellness system that suits their specific needs, including how to create a nutrition and fitness plan tailored around their health goals.

BCDI physical therapist Amanda hosted an educational session titled "Navigating the 4th Trimester with a Bleeding Disorder." This talk focused on physical therapy for people with bleeding disorders as they recover from childbirth delivery and the physical challenges that can be experienced during the early phases of parenthood.

BEACON SPOTLIGHT

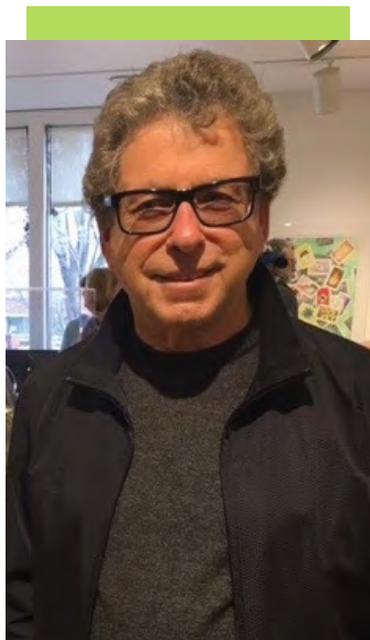
STEPHEN KAUFMAN

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

Stephen Kaufman has received comprehensive care for his ITP condition at BCDI since 2017. But that is just the beginning of Stephen's journey with ITP. That is because Stephen, who is 80 years old, has lived with his ITP condition for 70 years.



When Stephen was 10 years old, his parents became concerned that he was bruising easily. After various interactions with general practitioners and blood disorder specialists, doctors discovered low platelet counts which led to a diagnosis of Immune Thrombocytopenia Purpura- or ITP as it is commonly known.



"70 years ago is a long time and they didn't really know all that much about ITP. It wasn't until much, much later in life that the concern grew a little more dire," Stephen said. "Dr. Tarantino did a full workup of it and my genetics, my familial history, as well as my blood cells and what we've achieved is a safe level for me to, to engage in in life."

Living in Urbana, Illinois, Stephen is seen by BCDI's comprehensive care team every year. In each visit, patients are seen by a hematologist, advanced practice provider, nurse, social worker, registered dietitian, dentist and immunologist. BCDI's on-site pharmacy works together with the clinical staff to provide medications and deliver directly to patients.

"To me, that level of care and attention is welcomed and is shocking because I never experienced that in the current healthcare system," Stephen said. "I continue to have my platelets monitored here locally and those results are reported to BCDI and somehow magically a dose of medicine appears the next day on my doorstep and delivered by a very thoughtful team of people at the Institute. I just find this level of care astonishing and obviously very, very welcome."

"Dr. Tarantino and his team are just exceptional in providing the information one needs to explain the disease, providing the information to diagnose it, providing information for the best treatment for you," Stephen added. "I know I can pick up the phone right now and talk to someone there at the institute if I have a question, and that is extraordinary. I just can't say enough about how I appreciate their availability, their dedication, and how up to date they are. It's an hour and a half trip for me (to drive to Peoria) and I always willingly make it because they're all focused on me. It's a team approach and the care that Dr. Tarantino and his team have afforded me is the kind of care we all want seek, and it just could not be better."

BEACON BOTTOM LINE

INTRODUCING THE DEVERAUX HUBBARD II BLOOD CLOT PREVENTION AND TREATMENT ACT

The Bleeding and Clotting Disorders Institute facilitated a press conference with State Representative Jehan Gordon-Booth and the Deveraux Hubbard II Foundation on October 16 to highlight the challenges and treatment for individuals impacted by blood disorders and discussed newly introduced legislation to reduce mortality in Illinois.

Rep. Gordon-Booth introduced House Bill 4172 on Friday October 13, which seeks to increase education efforts, boost awareness and help with the diagnosis of deep vein thrombosis. House Bill 4172, which is also known as the “Deveraux Hubbard II Blood Clot Prevention and Treatment Act,” was introduced and filed on World Thrombosis Day, which is a day of awareness that aims to reduce the incidence of morbidity and mortality caused by blood clots.



“The fact that we have this opportunity with the leadership of Representative Gordon-Booth to even think that a comprehensive, integrated effort is going to do something to better this is tremendous. It’s an answer to a prayer,” said BCDI CEO/CMO Dr. Michael Tarantino. “To be honest, BCDI serves about 7,000 people all throughout the downstate area. Most of those people have blood clot issues and to have the government’s support in a whole new light, a focus to really address this problem and to do formally what the Hubbard’s have been doing for the last ten years in saving lives by helping people recognize the risks, steering them to the right place to get medical attention for this is priceless.”

The founders of the Deveraux Hubbard II Foundation, Deveraux Hubbard and Kristie Hubbard, helped pave the way for this new legislation. The Hubbard's tragically lost their son in 2013, Deveraux Hubbard II, from a pulmonary embolism caused by a blood clot. He was a 19-year-old sophomore at Southern Illinois University in Carbondale.

"He developed a blood clot that moved to his lungs and broke off and actually killed him instantly in our arms," said Kristie Hubbard. "And that is what is called a pulmonary embolism. We learned that tragically. But since that day, we have worked hard to teach others the signs and symptoms so that they would not have to suffer the way our family has suffered. And it's funny to say we've been blessed, but any time a person can live because of the knowledge we share, we call that a blessing. So, that's our commitment and this opportunity to have this be a legislative act in Illinois, wow. We could not be more elated."

Rep. Gordon-Booth was inspired by the Hubbard Family to introduce this new legislation, which has the support of the Illinois Department of Public Health.



"With House Bill 4172, we are looking to do two things. Specifically, we're looking to add additional resources and revenue specific to the education and awareness of pulmonary embolisms," Rep Gordon-Booth said. "We want to be able to ensure that folks around the state of Illinois have the ability to provide this education and advocacy at a much higher level. We know that this saves lives, and we want to be able to prevent loss of life wherever we can. The second leg of this legislation will require the Illinois Department of Public Health to engage in an advisory committee that will continue and go down a path of research and advisory. The advisory committee will also begin to funnel information back to the appropriations side relative to the education and the advocacy. So those two arms will work hand in hand to hopefully continue to prevent the loss of life unnecessarily."

BCDI is honored to be a part of this tremendous moment of recognition for a problem that our staff faces every day. 60,000 people per year are burdened with pulmonary embolisms, and it is estimated that 10,000 – 20,000 people a year die from pulmonary embolisms. In total, BCDI serves over 7,000 patients across Illinois and throughout the country.

"I'm thankful for the critical role BCDI plays not just for residents in Peoria, but for thousands across the state," Rep. Gordon-Booth added. "We're so blessed in this community because outside of Chicago, BCDI happens to be the only facility that provides this level of specialized care for individuals dealing with blood clot disorders. It is absolutely a blessing to be a resident of this region. So thank you to BCDI for your leadership."

BEACON TIPS

OPEN ENROLLMENT FOR 2024 INSURANCE NOW AVAILABLE

As we approach the end of the calendar year and the insurance open enrollment season, there are a few questions you need to ask when choosing an insurance plan if you have a bleeding or clotting disorder. Open enrollment for your 2024 insurance coverage is available November 1, 2023 through January 15, 2024.

How do you get your insurance?

Do you get your insurance from an employer sponsored plan, through the ACA marketplace, or through a public payer such as Medicare or Medicaid? Where your insurance comes from will determine the laws that govern coverage requirements.

Are your preferred providers (including your HTC) in network?

Providers not within your network will often require you to pay a significantly higher co-insurance or may not be covered at all.

Is your preferred pharmacy in network?

While your healthcare providers may all be in network, many times your preferred pharmacy or pharmacies are not. As more and more payers purchase pharmacies and specialty pharmacies, they tend to require patients use a narrow network of pharmacies, especially for things like clotting factor. This can create a delay in care for acute needs.

Are your medications covered?

In an attempt to fight rising drug costs, many self-funded employer plans are using tactics we call alternative funding methods to circumvent paying for specialty drugs. These programs require a plan to exclude coverage for these drugs. Once the coverage does not exist, the patient is asked to sign power of attorney over to a broker as well as provide financial documents so that the broker can enroll the patient in a manufacturer's charity care program. These programs, intended for those who are experiencing a lapse in insurance coverage, have a finite amount of funds and are intended as a short-term stopgap when no other options to access lifesaving medications exist. Program drug is also not intended for urgent bleed situations as it typically takes 3-5 business days after the patient requests medication for that medication (minus needed infusion supplies in many cases) to arrive. This can create unintended consequences such as bleed induced joint damage or lead the patient to seek alternative care in the emergency department to obtain their medication. BCDI as well as patient advocacy organizations such as the National Bleeding Disorders Foundation and the Hemophilia Federation of America oppose the use of these models in employer sponsored plans and encourage all patients to make their voices heard about the harm they cause.

Looking for more information? We have more details, including a write-up about whether or not manufacturer copay assistance counts towards your deductible or max out of pocket, on our website. We also have our "Understanding Your Insurance" booklet, which includes 16 pages of important insurance questions, worksheets and even a health insurance terms glossary. You can find that workbook and more information at ilbcdi.org/news/open-enrollment-for-2024-insurance-now-available or by scanning the QR code!

The health insurance market continues to become more opaque each year. BCDI is here for you if you need assistance understanding your health insurance or your options during open enrollment.



BEACON BULLETIN

BCDI FAMILY DAY



Education and advocacy are at the heart of BCDI's mission of providing integrated, family-oriented care to individuals and families with bleeding, blood clotting and other blood disorders. BCDI's Family Day event was held on Sunday August 27 at a Peoria Chiefs baseball game at Dozer Park in Peoria. With over 200 attendees, it was an incredible day to spend with the BCDI community and provide education to our families.



Family Day 2023 began with attendees arriving at Dozer Park at 9:30 a.m. for registration and picked up a BCDI swag bag which included a custom BCDI hat. BCDI Provider Education began around 10 a.m., beginning with a session from BCDI CEO/CMO Dr. Michael Tarantino entitled "Why Comprehensive Care?" In this session, Dr. Tarantino explained the comprehensive care model that BCDI provides to its patients and gave insight to research that explains why comprehensive care is an integral part of BCDI. Following Dr. Tarantino's presentation, BCDI CFO/COO Becky Burns led a session explaining the current landscape regarding insurance, Registered Dietitian Beth Helmold presented a video regarding the BCDI Patient Wellness Program, Dr. Jonathan Roberts led a talk about the pros and cons of new technologies in bleeding disorders, Dr. Maria Espanol held a session about the future of anticoagulation and the BCDI Research Department gave an inside look at current research ongoing at the Institute.



Fun activities and games were also coordinated for teens and children during Family Day! Led by BCDI social worker Marsha Hurn, the teens group worked on a teens transition project. Four different kids groups participated in activities around Dozer Park- including face painting, balloon art, a do-it-yourself trail mix station and a custom baseball card making station.

At 12 p.m., BCDI invited all Family Day attendees to the right field pavilion at Dozer Park for lunch. Prior to the game, two BCDI Family Day guests threw out ceremonial first pitches! Silas and Xander did a fantastic job and even got to meet a player from the Chiefs and took home an autographed baseball. All Family Day attendees had the opportunity to enjoy the baseball game and perfect weather where the Peoria Chiefs beat the West Michigan Whitecaps 5-4.

From everyone at BCDI, we would like to thank all our Family Day attendees for joining us for a day full of education and fun! We loved having the opportunity to provide continued education about bleeding and clotting disorders to our community. We hope that you enjoyed the day as much as we did, and we are already looking forward to Family Day 2024!

BEACON SUPPORT

ITP PATIENT SUPPORT GROUP AT BCDI

Did you know? BCDI has an ITP Patient Support Group! BCDI provides patient support for ITP through our independent affiliation through the Platelet Disorder Support Association (PDSA). This support group meets virtually four times per year and was specifically created for BCDI patients with an ITP condition and their family members.

Through BCDI's ITP Patient Support Group, members receive updates on ITP treatment options, research and ongoing clinical studies from BCDI staff, while also receiving an overview of how ITP comprehensive care clinics operate and the critical role they play. Members of this patient support group also will provide guidance to BCDI on how to enhance and expand patient services. One of the biggest impacts this group has is providing a community to ITP patients. Living with an ITP diagnosis can feel isolating and hard to navigate. BCDI's ITP Patient Support Group allows individuals a forum to support one another in their health journeys!

Are you interested in becoming a member of the BCDI ITP Patient Support Group? It is free to join! Please contact BCDI's social worker, Marsha via phone at 309-692-5337 (extension 126) or through email at marsha@ilbcdi.org.



BEACON BRIEFS

BCDI NEWS/EVENTS

Save the Date! 13th Annual BCDI Trivia Night- April 19, 2024

BCDI is excited to announce the date and location of our 13th Annual Trivia Night Fundraiser! Please join us on Friday, April 19, 2024, and the Peoria Civic Center Ballroom for an evening like no other! To celebrate the 2024 edition of BCDI Trivia Night, this year's theme will be '24 Karat Gold'- so be sure to wear your favorite gold-themed attire! Trivia Night is a wonderful opportunity to join BCDI and the bleeding and clotting disorders community for a thrilling team-based trivia contest, exciting raffle prizes and contests, fun games, dinner and more! More information will be made available soon and registration will open at the beginning of 2024. If you are interested in attending BCDI Trivia Night 2024, please email matt@ilbcdi.org for more information!



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.*
- **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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www.ilbcdi.org/about-us/newsletter

