

# BLOOD TIES

Tri-State Bleeding Disorder Foundation

| 635 W. Seventh Street

| Suite 407

| Cincinnati, OH 45203

2nd Edition 2023



## Our Mission

Tri-State Bleeding Disorder Foundation is a chapter of the National Hemophilia Foundation, which is dedicated to finding better treatments and cures for bleeding and clotting disorders and to preventing the complications of these disorders through education, advocacy and research.

Dear TSBDF Friends and Family,

I want to start by saying how honored I am to be asked to fill the position of the next President of the Tri-State Bleeding Disorder Foundation. I must confess it is a little intimidating because my father Warren Peterson was the first President of the organization which eventually became the TSBDF. I never pictured myself trying to fill such big shoes. As Lisa Littner mentioned in her very kind introduction in the last issue of Blood Ties, I have been on the Board of Directors since 2016 and I have never met a more dedicated group of people in my life who are doing everything they can to make the lives of people living with bleeding disorders better. I also want to thank Lisa for her leadership through the pandemic years and her willingness to serve an extra year as President for continuity in such a tough time.

It has been another exciting year for the TSBDF and I won't repeat the events Lisa already highlighted in the last issue, but we did have our very successful Unite Walk in August raising just under \$25,000. There is still time to donate through the end of the year if you would like to do so.

Shortly after the walk, a few of us attended the National Hemophilia Foundation national conference in National Harbor, Maryland. The opening ceremony was dedicated to communicating the NHF leadership's desire to rebrand the NHF including a name change which more clearly communicated their mission was not just helping people with hemophilia, but all people with bleeding disorders. They decided on the name National Bleeding Disorders Foundation which fit right in with our Tri-State Bleeding Disorder Foundation name.

I look forward to all the opportunities we have to serving the bleeding disorders community in the future. We're already planning next year's events which will include the always popular Great Wolf Lodge in February. Hope to see you there!

Sincerely,  
Keith Peterson  
President  
TSBDF Board of Directors



## CONTENTS

2	President's Letter
3	OBDC Statehouse Day 2024
3	TSBDF Physician's Dinner
4	National Hemophilia Foundation Updates Name to National Bleeding Disorders Foundation
4	Science Corner
6	Unite Walk
8	TSBDF Donors
10	2023 TSBDF Scholarship Awards
12	Patient Events & News
	Back Cover
	2024 Calendar of Events

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The Ohio Bleeding Disorders Council Statehouse Day will be held on Wednesday, March 20th.

We will officially recognize March of 2024 as the first bleeding disorders awareness month in Ohio. So, it will be an exciting time for our families to gather at the Statehouse to spread awareness and share with our lawmaker's issues impacting our bleeding disorders community.

During the event, families will share their story and advocate for issues impacting our community with their elected officials in small group meetings and over a luncheon. While it is our goal that each family meet with their State Representative and Senator, because of scheduling issues this isn't always guaranteed. This year we are focusing on increasing access to the Complex Medical Health (formerly children with medical handicaps) treatment program up to age 26, banning the use of copay accumulators on health insurance plan designs, and addressing issues of delays in treatment and care because of the prior authorization process.

I hope you will join us for this very inspiring and impactful day of action. If you cannot make the day in Columbus, please reach out to me to schedule a meeting in your area with your elected official.

## Save the Date!



### Ohio Bleeding Disorder Council Ohio Statehouse Day Wednesday, March 20, 2024

Dinner and training will be provided on Tuesday, March 19th



Ohio Bleeding Disorders Council

**Statehouse Day is open to everyone!**

This year we are extending a special invitation to those who

- Depend on co-pay assistance
- Experience delays in treatment because of Prior Authorization denials
- Young adults 18-26 for the CMH increase

To RSVP please email:  
[obdcsvp@gmail.com](mailto:obdcsvp@gmail.com)

Please visit for registration information.  
[www.ohiobdc.org](http://www.ohiobdc.org)

## TSBDF Physician's Dinner

The TSBDF Physician's Dinner took place on Tuesday, September 5th at The Graduate Hotel. Dr. Jahnvi Gollamudi from UC's HTC and Dr. Maria Carter Febres from CCHMC HTC spoke on Women with Bleeding Disorders. Hematology and OBGYN physicians and nurse practitioners from were invited to learn more about women with bleeding disorders.

Dr. Gollamudi focused her presentation on the Management of Bleeding Disorders During Pregnancy and Dr. Carter Febres spoke about the Challenges of Hemophilia Carriers, vWD and Rare Bleeding Disorders for Adolescents, Young Adults.

Thank you to our sponsors! BioMarin, Genentech, HEMA Biologics, Novo Nordisk, Pfizer, Sanofi, and Takeda.



CCHMC, UC, and TriHealth providers at the TSBDF Physician's Dinner

# National Hemophilia Foundation Updates Name to National Bleeding Disorders Foundation



**Innovate | Educate | Advocate**

*The 75-year old foundation updates its name to reflect a more comprehensive mission.*

The National Hemophilia Foundation (NHF) recently changed its name to the National Bleeding Disorders Foundation (NBDF). Foundation leaders announced the change during the recent August 2023 Bleeding Disorders Conference, held in National Harbor, Maryland.

The foundation, created 75 years ago to help people living with hemophilia, has evolved to assist those living with other inheritable blood and bleeding disorders, including von Willebrand disease, rare factor deficiencies, and platelet disorders. The foundation supports both patients and their families through research, education, and advocacy, according to a statement released to announce the name change.

In recent years the foundation has addressed health equity issues in an effort to eliminate barriers to care for underserved populations. According to the foundation's statement, the rebrand to include all blood disorders "aims to address concerns around diversity, inclusion, and equity to ensure every person and family facing an inheritable blood or bleeding disorder has access to the advanced care and support they need – regardless of gender, age, ethnicity, location, or socioeconomic background – so they can achieve their highest level of health."

The National Bleeding Disorders Foundation also released a new logo to represent a wide range of inheritable blood and bleeding disorders, as well as a new tagline: **Innovate | Educate | Advocate**.

## Science Corner

### Exciting New Treatment Options Approved by the FDA for Hemophilia

Exciting new treatment options recently approved by the U.S. Food and Drug Administration (FDA) continue to expand bleed protection for persons with hemophilia. Joining emicizumab (Hemlibra™) approved by the FDA in 2017, and HemGenix™ the one-time gene therapy for the treatment of adults with hemophilia B approved in 2022, two exciting new therapies for hemophilia were recently approved by the FDA. These include a unique first-in-class bioengineered long-acting Factor VIII concentrate (ALTUVIIIIO™) which allows for once-weekly dosing for the prevention of bleeds (prophylaxis), and the newly approved gene therapy for adults with severe hemophilia A, Roctavian™ (valoctocogene roxaparvovec-rvox). These two new treatment options have been shown to dramatically reduce the bleed rates in persons with severe hemophilia A, while reducing the burden of prophylactic treatment and the need for frequent intravenous infusions.

#### ALTUVIIIIO

*FDA Approves Once-weekly ALTUVIIIIO, a New Class of Factor VIII Therapy for Hemophilia A That Offers Advanced Bleed Protection.*

On February 23, 2023, it was announced that the U.S. FDA had approved ALTUVIIIIO (Fc-VWF-XTEN Fusion Protein-ehtl), previously referred to as efanesoctocog alfa, a first-in-class, high-sustained factor VIII replacement therapy. ALTUVIIIIO was originally developed by Bioverativ, a company acquired in 2018 by Sanofi, which continued the drug's development in collaboration with Sobi. ALTUVIIIIO is indicated for routine prophylaxis and on-demand treatment to control bleeding episodes, as well as surgical management for adults and children with hemophilia A. ALTUVIIIIO is the first and only hemophilia A treatment that delivers normal to near-normal factor activity levels (over 40% levels) for most of the week with once-weekly dosing, and significantly reduces bleeds compared to factor VIII prophylaxis with previously available Factor VIII products.

ALTUVIIIIO is a novel recombinant factor VIII therapy designed with a 3 to 4-fold longer half-life (the time it takes the blood level to drop to one-half of the previous level) relative to standard and other extended half-life factor VIII products. In the blood, Factor VIII circulates tightly bound to von Willebrand factor (vWF). This vWF binding protects Factor VIII from being rapidly broken down and inactivated in the circulation, but links the half-life of Factor VIII to vWF which has a maximum half-life of about 15 hours. To overcome this 15-hour

limitation new strategies to prolong the circulating life of Factor VIII were investigated. ALTUVIIIIO was designed to be independent of vWF binding. In addition, two XTEN chemical chains (polypeptide-Fc chains) were added to reduce the breakdown rate of Factor VIII. These changes extended the survival of ALTUVIIIIO up to 4 times longer (average half-life 47 hours) compared to recombinant Factor VIII.

By replacing the need to infuse Factor VIII 2 to 3 times per week to prevent bleeds to once weekly infusions with ATUVIIIIO, the burden of prophylaxis for patients can be significantly reduced, while offering superior protection from bleeds.

#### ROCTAVIAN

*FDA Approves Roctavian™ Gene Therapy for Adults with Severe Hemophilia A*

On June 29, 2023 it was announced that the U.S. FDA had approved Roctavian an adeno-associated virus (AAV5)-based gene therapy for adults with severe hemophilia A. Roctavian, produced by BioMarin Pharmaceutical Inc., uses a modified virus called a vector to deliver a working copy of the factor VIII gene to liver cells to enable the body to produce clotting factor on its own. The modified virus does not contain viral DNA and does not cause disease in humans. Approval was based on the results of a global, phase III study (GENEr8-1). A three-year follow-up showed an 82.9% reduction in treated bleeds overall compared with baseline. While on Roctavian patients reported an average annualized bleeding rate of less than 1 spontaneous bleed/year and less than 1 bleed/year for joint bleeds. A majority of patients continued to respond for three years and beyond without the use of regular prophylaxis. Additional results from the study found Roctavian led to a 96.8% reduction in Factor VIII usage overall compared with baseline. Safety results demonstrated that Roctavian was well-tolerated. The most common laboratory abnormality was an elevation of liver enzyme levels in the majority of patients in the clinical trial requiring treatment with corticosteroids for an average duration of 35 weeks. BioMarin is committed to monitoring the long-term effects of treatment with an extension study that will follow all clinical trial participants for up to 15 years. As part of the development of Roctavian, BioMarin has worked with private and public payers in the U.S. to enable access to this first-in-kind treatment, with the goal of ensuring that every eligible adult interested in Roctavian is able to receive treatment. The company is also working closely with U.S. HTC's to ensure that the centers are prepared to administer Roctavian now that FDA approval has been granted.



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# UNITE Walk

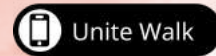
Our 6th Annual Unite Walk took place on Saturday, August 12th at Mt. Echo Park. We had over 200 participants and so far we've raised just under \$25,000!! Thank you to everyone who supported the walk this year!

We would like to take a moment to recognize our Teams and Fundraising Champions! Our top 3 teams by way of registered participants who raised an average of \$25 per person were Team Clark and Calvin, The Luke Skywalker's, The Steel and Flick Family, and The Gunz Walkers. Our top individual fundraisers were Les Gunzenhaeuser, Lindsay Schulte, Olivia Traficanti, and Lindsey Long.

Our top 3 team fundraisers were The Gunz Walkers, Brynn Lucky 13, Cats for the Cure, and Team Lions, Tigers and Bears.

The walk website will remain open through the end of the year.

*Scan here to donate today!*



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TEAM CLARK AND CALVIN**



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Sanofi Community Relations and Education (CoRe) Managers are dedicated professionals who can provide personalized education about ALTUVIIIIO, and point you toward helpful support and resources.



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MAT-US-2305908-v1.0-07/2023

# TSBDF Organizational & Foundation Contributors

We would like to thank everyone that has contributed to Tri-State Bleeding Disorder Foundation (TSBDF). You have helped to make TSBDF a source of education and support for the bleeding disorder community. This page is only a small token of our appreciation for everyone's contributions, whether they are financial, in kind, or other. We truly appreciate all that you have given!

Donations listed are from 12/22-10/23

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## Donor Highlight

TSBDF would like to thank Kathryn French for her dedication to the Greater Cincinnati/Northern Kentucky bleeding disorder community. Ms. French made a Lead Donation to the Dr. Joseph E. Palascak Endowed Chair Fund during our endowment campaign, which was matched by our community. Her gift ultimately led TSBDF to reach our goal and secure funding for the Dr. Joseph E. Palascak Endowed Chair at the University of Cincinnati's Hemophilia Treatment Center.

Her support of the bleeding community has continued as she graciously donates to her son-in-law, Dr. Les Gunzenhaeuser's, walk team, the GUNZ WALKERS, each year. TSBDF is able to offer important education and support services to the bleeding disorder community because of Ms. French's generosity and other donors like her.

If you would like to learn more about ways you can support the community please contact our office.



# TSBDF Individual Contributors

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*Thank  
you!*

# 2023 TSBDF Scholarship Awards

By Dr. Ralph Gruppo

## *Results of the Annual TSBDF First-Place Awards for the T.D. Hughes, Jr. and Gina Stack Memorial Scholarships to Skyler Ficklin and Avery Daniels*

Each year the Tri-State Bleeding Disorder Foundation (TSBDF) awards two types of scholarships: the T.D. Hughes, Jr. Scholarship, and the Gina Stack Memorial Scholarship. These scholarships are available to any person with a bleeding disorder and their immediate family members. The applicant must be seeking full-time enrollment in a university, college, or technical school or be enrolled as a full-time student in a graduate school program. Applicants for the Gina Stack Memorial Scholarship must be pursuing a degree program with a focus on healthcare or the medical profession. This year the first-place award for each of the scholarships was \$2,500. Partial scholarships were also awarded to the runners-up for each of the scholarships. The scholarship committee scored each of the applicants based on 5 categories: Academic Achievement, Humanistic Qualities, Overall Quality, Applicant's Statement, and a Discretionary Category which included the strength of the applicant's reference letter, financial need, and special circumstances.

For 2023, the first-place awardee for the T. D. Hughes, Jr. Scholarship was Skyler Ficklin. Skyler is attending the University of Cincinnati College Conservatory of Music, Baccalaureate Program to major in Media Production. Runners-up awards went to Avery Daniels, Max Daniels, and Mary Capone.

The first-place awardee for the Gina Stack Memorial Scholarship was Avery Daniels. Avery is attending her second year at Indiana University in the School of Nursing. Runners-up awards went to Max Daniels and Mary Capone. Max will be attending Indiana University as a freshman with the goal to graduate with a BS degree in chemistry, and then apply to pharmacy school with the eventual goal to be a pharmacist. Mary is attending Miami University – Hamilton as a sophomore in the Applied Biology Baccalaureate Program with the eventual goal to be an anesthesiologist assistant.

Through the generosity of Dr. and Mrs. Peter G. Ruehlman, the University of Cincinnati offers a \$5,000 scholarship to a student living with a bleeding disorder. This scholarship is available to a student enrolled full-time at any of the U.C. colleges. This year's Dr. Peter G. Ruehlman Scholarship was awarded to Skyler Ficklin.

Congratulations to all of our scholarship winners!

### Meet Our Scholarship Recipients

#### Skyler Ficklin

I'm a 2nd year student studying Media Production at the University of Cincinnati and I plan on continuing this collegiate education. I'm going to be taking some higher-level classes in the next semesters to further my study of Film. To become well educated in multiple areas, I plan on enrolling in language classes and pursuing a minor in IT. I plan to work internships where I can learn from and work with professionals in the industry. Additionally, I am looking to start working on my own projects to further develop my skills and gain more experience as well. With these opportunities, I'm hoping to gain a deeper understanding of storytelling and its tools to prepare myself for a successful career.

#### *How has having a bleeding disorder impacted your educational experience?*

Having a bleeding disorder has further empowered and driven me to seek out and put effort into getting a good education. Being a part of this new community has shown me more of what it means to be in a community. I want to have the education to take part in fighting for access to resources people in this community need and telling their stories. I'm interested in documentary filmmaking and this new connection to a group of people drives home to me the importance of storytelling and its impact on the world.

#### *What have been the positive aspects of having a bleeding disorder?*

It was just a little over a year ago that I was diagnosed with Mild Hemophilia. Since I've only known for such a short part of my life it is hard to say what have been the positive aspects of having a bleeding disorder, but I can point out a couple of things I have seen this year. When I was first diagnosed a whole new world of support systems were opened up to me. Foundations like this Tri-State Bleeding Disorder Foundation and the National Hemophilia Foundation have many resources I've never known before. There are social workers and care managers and doctors. There are support groups and people I've met with bleeding disorders. There are more people and tools around me than ever to help me succeed in life and in supporting myself, growing myself, and helping others and that is amazing. There was also a young adult program where I got to hang out with some of those people, learn, and have fun at the Great Wolf Lodge for free. That was pretty cool. There's also this scholarship helping me to get my education which is a great positive. Even just in one year, there have been awesome positive aspects of having a bleeding disorder.





**Avery Daniels**

I am currently a Nursing Student at Indiana University and will be graduating in 2026 with my Bachelor of Science in Nursing.



I am inspired to further my education, specifically in nursing for a few reasons. I chose nursing because I want to help others who really need it. My family is full of healthcare providers, my mom and dad both work in the field and even my grandma was a nurse! Within nursing, my goal is to eventually focus specifically on oncology which I have become passionate about since attending Camp Joy with my younger brother.

*How has having a bleeding disorder (or having a family member with a bleeding disorder) impacted your educational experience?*

Having a sibling with hemophilia has taught me so many things that I wouldn't have ever learned if he were not affected. I get to witness daily the way he lives his life with the disorder and have even learned of my chances of being a carrier and someday having children of my own who could possibly be affected. Learning how this genetic disorder works and runs through the family is fascinating!

*What have been the positive aspects of having a bleeding disorder (or having a family member with a bleeding disorder)?*

Although my brother lives his life with hemophilia, there are certain things that have come positively from it. Thanks to Cincinnati Children's Hospital and TSBDF my brother and I were able to attend Camp Joy together for four years. The Tri State Bleeding Disorder Foundation also does a lot for our family including various educational events to keep our family involved and connected. One of the most positive things about being around my brother's bleeding disorder is that it has heavily influenced my chosen career path!

**Max Daniels**

I am studying chemistry at Indiana University. Having hemophilia interested me in the field of medicine, so then I chose to be a pharmacist in the future.

*What have been the positive aspects of having a bleeding disorder?*

It has connected me with great people and inspired me to help others just as much as I have been taken care of by Children's.



**Mary Capone**

After graduating with a bachelor's in applied biology and a minor in commerce, I will be furthering my education in a grad school program to become an anesthesiologist assistant.

Since having a bleeding disorder, I had a lot of doctors' appointments when I was younger. I always knew I wanted to go into the medical field so I could be there for patients and make it a more comforting place for them like the doctors did for me at Cincinnati Children's hospital.

*What have been the positive aspects of having a bleeding disorder?*

The positive aspects of having a bleeding disorder and having family members with the same bleeding disorder helps me to know that I am not alone. We are all going through the same thing and have an amazing support system.

# Patient Events & News

## InfoTrust Foundation's Thanksgiving Program by Lisa Littner

Thanksgiving time is a time of giving for many. For the employees of TSBDF Board of Director, Alex Yastrebenetsky, it is a time to help patients and families at Cincinnati Children's Hospital Cancer and Blood Disease Institute (CBDI).

"In 2013, we launched our first Basket Brigade in our local community. The initial steps involved recruiting volunteers, collecting donations, and selecting families who could benefit from our gesture of love. We soon discovered immense power in unity, and our small team began to grow," states Alex.

On the designated Basket Brigade Day, the InfoTrust employee group assembled in a central location, each armed with a basket filled with carefully chosen items. Alex shares "There was a sense of excitement and purpose that permeated the atmosphere. As we knocked on doors and presented these gift baskets, the reactions from the families we encountered were heartwarming. Tears of gratitude, hugs, and smiles confirmed that we were on the right path."

The success of InfoTrust's first Basket Brigade was just the beginning. They decided to continue this tradition year after year, but they also had bigger aspirations. Inspired by the impact that they had witnessed, they wanted to expand their reach beyond our local community. In 2018, they established the InfoTrust Foundation to grow and continue their charitable efforts. "At InfoTrust, we firmly believe in leveraging our success to give back to the communities in which our team members live and work, so we have quarterly activities that help our team members live our Purpose," said Alex.

Cincinnati Children's CBDI social worker, Molli Monk, shares, "Each year InfoTrust provides a generous donation to the CBDI patients and families for Thanksgiving. This year was no different." Through the generosity of InfoTrust, families that need assistance during the holidays received a Kroger gift card for food help for the Thanksgiving holiday. "This is something that many of our patients and families look forward to each year, especially families that cannot afford to purchase a meal on their own. We are thankful and blessed to be able to utilize this valuable resource and appreciate all that InfoTrust does for us each and every year", said Molli.

In 2022, the Foundation donated \$15,840 for a total of 892 baskets. They look forward to many more years of spreading love and hope through this beautiful initiative and continuing to be part of a global movement that started with a simple idea in 2012.



*Alex was born in the Ukraine with severe hemophilia A. He was cared for by Dr. Gruppo, TSBDF Board of Director and former Cincinnati Children's Hospital medical director. Alex credits the amazing care of the CCHMC staff and the help that he received along the way from many people as the reasons why he is where he is today. "Now, as a co-founder and CEO of a growing global technology company, it is my time and responsibility to give back," said Alex. "It gives me incredible pleasure to also involve my kids with as many of our community projects as possible".*

*TSBDF is grateful to InfoTrust for their support and generosity including their contribution to the redevelopment of our website in 2022.*



National Bleeding Disorders Foundation  
Annual Bleeding Disorders Conference  
By Lindsay Schulte



We are so thankful for our local chapter's invitation to attend the National Bleeding Disorder Foundation's Annual Bleeding Disorders Conference, this past August, in Washington, DC. This was our first time attending and we went in with limited exposure and experience. We were excited to connect with others in the bleeding disorder community, on a national level, while learning more about this world we became a part of 4 years ago. The trip superseded our expectations!

We have 3 children: Luke, 8, Nate, 6, and Brynn 4, who were very excited to attend the conference, check out a new city, and of course stay at a hotel and swim in the pool! Brynn has an ultra-rare bleeding disorder, FACTOR XIII, and has an existing inhibitor. We were eager and curious to see other individuals in the US, who may be attending, with the same or similar rare diagnosis.

During the conference, we were able to utilize the childcare option, as we explored the various sessions that piqued our interest. Our favorite session highlighted the ultra-rare bleeding disorders that exist in our population around the world. There was a panel discussion that was exceptionally helpful, with individuals or care givers who have navigated, and continue to navigate, a life with a rare diagnosis. Brynn may be 1 in 5 million with her diagnosis, but 3 people in this break out session had Factor XIII. That was powerful!

In addition, we attended breakout sessions regarding Gene Therapy, and "Managing Life as a Caregiver". This focused on working through the complexity that comes with a life-long diagnosis. The panel discussions were raw, vulnerable, and refreshing!

We learned how the National Bleeding Disorder community is inclusive and supportive. The conference had physicians, medical staff, chapters from across the country, and families attend. Industry was present since they sponsored the event. The exhibit hall hosted by these industry sponsors was INCREDIBLE – our kid's FAVORITE part! My kids enjoyed going from booth to booth playing games, getting their face painted, eating treats, and receiving information regarding the latest research, products, and data. See pic!

Overall, our family was able to enjoy a getaway and make memories. We were able to learn more about the world of bleeding disorders. We were able to see the White House, the Capitol building, explore the Air and Space Museum, and even see the Pandas at the ZOO. The conference and trip were positive, an attitude we try to have regarding Brynn's diagnosis ALWAYS! I would recommend, if given the opportunity, attend!

We are so thankful to the Tri State Bleeding Disorder Chapter for being a steadfast support for our family. We know we are not alone on this journey with Brynn!



Family Education Day at Kings Island

TSBDF hosted Family Education Day at Kings Island on Saturday, June 24th. Over 25 patient families attended the event including many who were new to the bleeding disorder community. Families enjoyed lunch and time together. Each family was given a sponsor passport card. If they received a stamp from each sponsor in attendance, they were entered for a chance to win one of two gift cards. It gave patients and families a chance to learn about all the therapies available for bleeding disorders.

Thank you to our sponsors for supporting this event!

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# Patient Events & News - continued

## TSBDF & CCHMC Educational Dinner By Lisa Littner

Insurance is always an important educational topic for people with a bleeding disorder and their families. As many of us know, bleeding disorder treatment medications are costly, and having good insurance coverage is so important. Insurance issues that may impact on people with a bleeding disorder are ever-changing and it is so important to stay on top of things.

On September 13th, TSBDF and CCHMC hosted an educational dinner at Montgomery Inn restaurant, and Randi Clites, Ohio Bleeding Disorder Council State Policy Director, was the speaker. Randi spoke about her personal experience being a mother of a young adult with hemophilia and spoke about her experience as a State Representative for Ohio. She also spoke about some current trends with insurance.

Some key takeaways from Randi's presentation included:

- It's important to read and review your Explanation of Benefits (EOB) summary that is mailed or emailed to you.
- Find out if you have a copayment accumulator on your plan. If you have an accumulator, a copayment assistance program won't count toward your out-of-pocket deductible. This can make paying for your bleeding disorder medications very costly.
- Be cautious of alternative funding programs. These programs connect patients to a third-party vendor. With an alternative funding program, medications may not be covered by the insurance and the third party may work with people to connect them to the patient assistance programs.

Randi also highlighted the Complex Medical Health (Children with Medical Handicaps) for Ohio children and young adults (up to the age of 25) as a resource for insurance coverage. Additionally, she spoke about the Ohio Delta Dental program for people with a bleeding disorder (and their families) get their care from an Ohio HTC and do not have dental insurance.



## Ask the Doc/Annual Meeting

The TSBDF Ask the Doc/Annual Meeting took place on Thursday, November 9th at The Phoenix in downtown Cincinnati. There were over \_\_\_ patients/family members who attended the event.

Dr. Eric Mullins from CCHMC HTC and Dr. Kristine Karkoska from UC's HTC made up our panel for this event. Both of the physicians took the time to talk about current therapies and research and then took questions from the audience.



CCHMC Staff

We want to thank our sponsors who helped make this event possible:

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**Saturday 1:22 pm**  
Swinging in the  
backyard with mom  
Evan, living with  
hemophilia A

Not an actual patient

## WE'RE IN THIS TOGETHER.

**Let's make today brilliant.**

Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world, is stronger than ever.

[bleedingdisorders.com](https://bleedingdisorders.com)



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## Calendar of Events 2024

Follow us on Facebook and visit our website [www.TSBDF.com](http://www.TSBDF.com) to be the first to receive chapter updates and program announcements.

**February 24th-25th**

**TSBDF Family Education Conference at  
Great Wolf Lodge**

**March 6th-8th**

**NBDF Washington Days**

**March 20th**

**Ohio Statehouse Day**

**September 12th-14th**

**NBDF Bleeding Disorders Conference**

Save the date for next year's Unite Walk.  
The 7th Annual Unite Walk will be held  
Saturday, August 17th, 2024  
at Mt Echo Park.