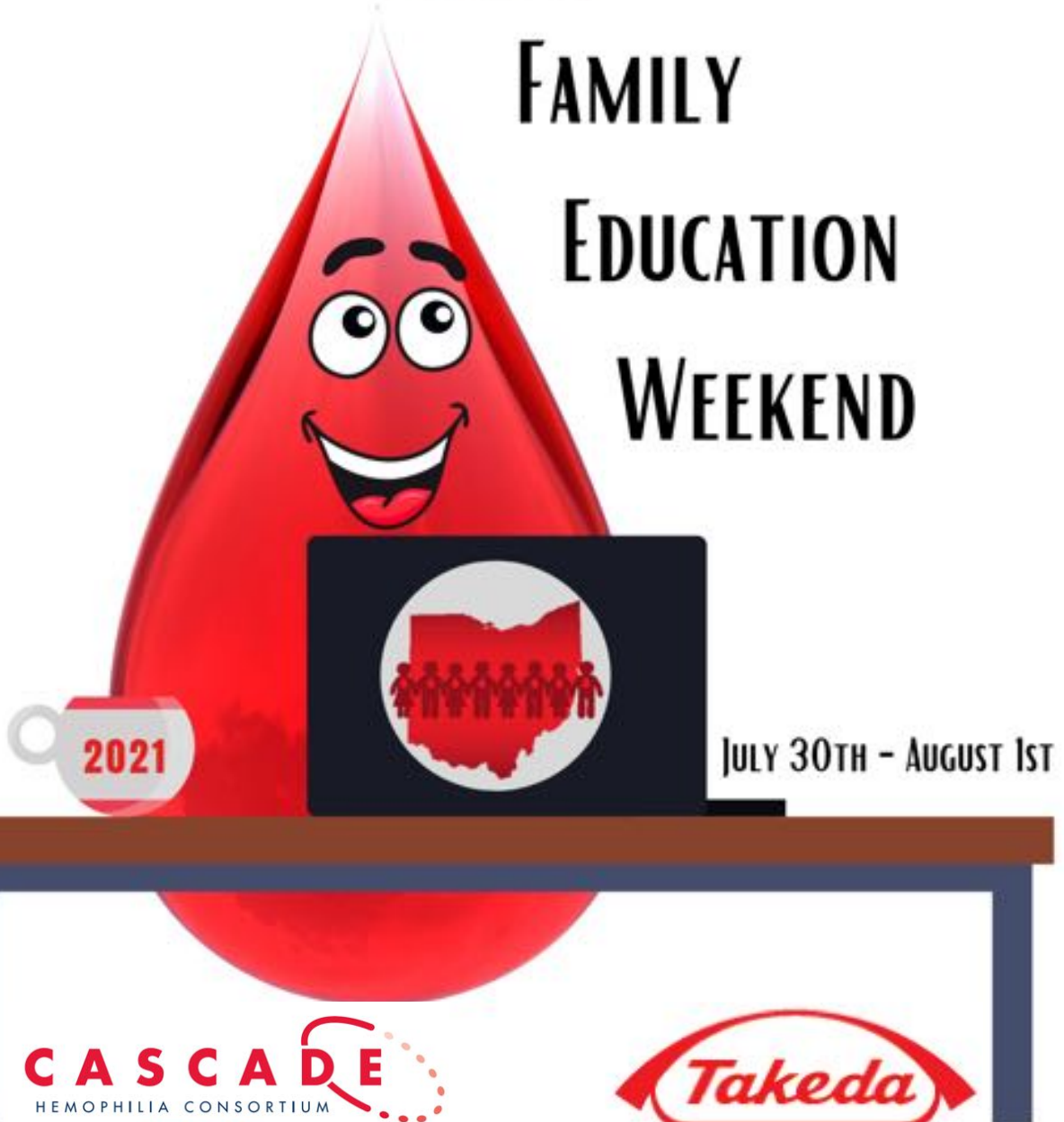


FamOHIO



KEEPING OHIO BLEEDING DISORDER
FAMILIES CONNECTED SINCE 1992

FAMILY EDUCATION WEEKEND



CASCADE
HEMOPHILIA CONSORTIUM
SINCE 1994



Dear Friends,

It is with great pleasure as President of FAMOHIO I welcome you to our 2021 program. While the past 16 months have been a bit scary or trying for many of us, I am very thankful to see that things are beginning to open back up and return to somewhat of a norm.

Even though this year our program remains virtual it has expanded from a one evening event to an entire weekend full of fun and learning. We have a lot of really exciting sessions planned thanks to the hard work and dedication of our Board, volunteers and sponsors. Please take this time to engage in these opportunities whether it be to learn something new, share some personal thoughts and experiences, connect with new friends or reconnect with old friends.

Thanks,
Tina Ascough
FAMOHIO Board President



POST CONFERENCE TRIVIA CONTEST

A LINK WILL BE SENT TO YOU WHEN THE CONFERENCE ENDS SO YOU CAN ENTER OUR TRIVIA CONTEST. QUESTIONS WILL INCLUDE VISITS TO OUR SPONSORS' WEBSITES, INFORMATION FROM OUR EDUCATION PROGRAMS AND FACTS ABOUT FAMOHIO. PRIZES WILL BE AWARDED TO THE TOP 3 WINNERS.

A GIFT FROM THE BOARD OF FAMOHIO

Each family attending the Family Education Weekend will receive a free copy of "The Anxiety First Aid Kit".

"If you're feeling unprecedented levels of stress and anxiety right now, please know that you aren't alone. In these extreme and uncertain times, it's natural to be in a constant state of mental and physical strain. Whether you're dealing with job loss, a sick loved one, or just feeling the weight of the world during your 2 a.m. — you need quick tools you can use right now, whenever and wherever you are, to lower stress and soothe anxiety. This emergency kit has you covered."



Hope you enjoy!

Join Zoom Meeting: <https://zoom.us/j/96025979164>

FAMOHIO FOUNDING FATHERS

In March of 1992, during the AIDS (acquired immunodeficiency syndrome) crises, six men came together to discuss their future and the future of their blood brothers. These men all carried the diagnosis of hemophilia and as a result of treatment for hemophilia had contracted HIV (human immunodeficiency virus). Instead of wallowing in self-pity they channeled their anger and feelings toward a positive goal. These men believed education was the key to ensuring the future for all people affected with bleeding disorders. In the summer of 1992, their creation, a state-wide, educational symposium was held called FAMOHIO. That year, FAMOHIO was the acronym for “first annual meeting of hemophiliacs in Ohio.” Going forward, FAMOHIO became known as “family annual meeting of hemophiliacs in Ohio.”

In the beginning the attendees generally carried the diagnosis of hemophilia. As time progressed the meeting grew in size to include people and families living or treated in Ohio with numerous bleeding disorders. The FAMOHIO founders believed that an annual meeting of people/families with bleeding disorders provided opportunities for shared information and increased knowledge through education and camaraderie. The current FAMOHIO board shares the founders’ beliefs.

The positive rippling effects of FAMOHIO are difficult to quantify. However, attendees largely agree that the FAMOHIO experience provides increased knowledge and a better understanding of how to live with a bleeding disorder.

FAMOHIO BOARD OF DIRECTORS

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Dwanna Rutter

Rick Sites

Jodi Skinner

Event Coordinator

Lisa Raterman

FAMOHIO AWARDS

The six founding fathers of FAMOHIO were active and strong advocates of the bleeding disorder community. These brave men knew firsthand what having a bleeding disorder entailed in a time when treatment was very limited.

To honor our great founders and current advocates, a series of awards have been created and are awarded annually. On the FAMOHIO website the description of awards are listed. We wholeheartedly accept nominations and would love to review any nominations we receive. Please consider nominating someone who has helped you on your journey.

The 2020-2021 award winners will be presented on Saturday evening during our program,

The highest award given by FAMOHIO, Inc. is the IRA GAFFIN MEMORIAL AWARD. This award is presented to an individual who has provided extraordinary voluntary service to the hemophilia community. This merit based award is offered once each year and is open to any individual or couple whose unstinting service on behalf of the hemophilia community of Ohio exemplifies the generous spirit of Ira Gaffin. The following names are the awardees who have achieved this great honor.

2021 Coy White	2007: Polly Partin-Welch
2020: Sandra Hibner	2006: Randy Clites
2019: Amy Dunn, MD	2005: Linda Wacha
2018: Josh and Krista Crossgrove	2004: Ruth Saylor
2017: Elizabeth Miller	2003: Sylvia Jordan
2016: Cindy Michael	2001: Jim Sites
2015: Glenn Pierce, MD, PhD	2002: Joseph Palascek, MD
2014: Karen Gillespie	2000: Bill Dennis
2013: Les and Gloria Gutter	1999: Rick Sites
2012: (none awarded)	1998: Michael Para, MD
2011: Teresa Bridges Rutter, Madeline Heffner, & Nancy Duffy	1997: Ralph Gruppo, MD
2010: Elizabeth Billow	1996: Dirk Scheerhorn, PhD
2009: Dena Shepard	1995: Paul and Rosie Haas
2008: (none awarded)	1994: Tom & Monica Burr

LES GUTTER MEMORIAL SCHOLARSHIP

2013, the Les Gutter Memorial Scholarship was created in memory of Les Gutter, who was the dedicated treasurer of FAMOHIO for more than twenty-years. Les's financial expertise, attention to detail, and strong dedication helped ensure the continued success of FAMOHIO, Inc. In addition to Les's financial expertise, his spirit of volunteerism was most commendable. Les was always one of the first to volunteer.

FAMOHIO strives to award at least one \$2,000 scholarship yearly and many years have had the resources to award additional scholarships. The board of FAMOHIO and the members of the scholarship committee acknowledge the many challenges students face during their journey to complete a post secondary educational program or beyond. It is hoped that financial assistance will help recipients continue their quest for knowledge and attain their dreams.

The FAMOHIO Les Gutter Memorial Scholarship is open to any person who holds a coagulation disorder diagnosis, i.e., hemophilia, von Willebrand disease or other serious inherited anti and pro coagulation disorders, who receives treatment at a federally recognized hemophilia treatment center (HTC) in Ohio, living currently in Ohio or in an Ohio HTC's service area, and is seeking post-secondary education at a university/college or technical school or are enrolled in a graduate program.

In 2020, five \$4,000 scholarships were awarded. The winners for 2021 will be announced later this year.

SPLIT THE POT



Just announced – the **WINNER OF THE SPLIT THE POT WILL RECEIVE A GUARANTEED \$250** thanks to some offline purchases we've received this week!

- Depending on additional purchases, online or off, the pot could go even higher, so don't forget to get your tickets.
- You must be in the State of Ohio to purchase online. If you live outside the state and would like to purchase tickets, please email at FAMOHIOinfo@gmail.com and we will make arrangements.
- The drawing will be during the wrap up on Sunday around 3pm.
- Winner does not need to be present to win.

Tickets can be found at www.winhalf.com/famohio

2021 SPONSORS

PLATINUM SPONSORS



GOLD SPONSOR



SILVER SPONSORS

CSL BEHRING
NATIONWIDE CHILDREN'S

BRONZE SPONSORS

ACCREDITO EXPRESS SCRIPTS
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BAYER
BIOMARIN
GRIFOLS

OCTAPHARMA
PFIZER
SANOFI GENZYME
SPARK

FRIENDS

COLBURN-KEENAN

AGENDA 2021

All Programs will be held on Zoom – the same link will be used all weekend. You can log off and on as needed. In order to participate in multiple break out rooms/sessions at the same time you will need separate devices for each attendee.

**Join Zoom Meeting: <https://zoom.us/j/96025979164>
To call in: 1-929-436-2866, Meeting ID: 960 2597 9164**

Certain sessions will have door prize drawings – you must be present during that session and at the time of the drawing to win. List of drawings is on page 9.

PROGRAM

Friday, July 30, 2021

- 5:45pm Zoom opens for people to network/get acquainted (optional)
- 6:00pm Welcome - overview of program
Introduce Takeda - Platinum Sponsor
Denny Baker and Arnold: Show and Tell Game
Introduce Cascade - Platinum Sponsor
Panel of experts to talk about 340b Programs and Advocacy
Denny and Arnold: Show and Tell Game
Introduce Novo - Gold Sponsor
Announce winner for this evening's drawing, overview of tomorrow's program
- 8:00pm Break-out rooms will stay open as long as people want
Young Adults - One stage to the next program presented by Takeda
Teens/Crews Nest
Womens Comfort Room
Mens Den

Saturday, July 31st

- 9:45am Zoom opens for people to network/get acquainted (optional)
- 10:00am Welcome
Plenary Session – Surviving Brain to Thriving Brain: Let's Talk About it with
Debbie de la Riva
- 11:00am Education Session - Von Willebrand Disease and Rare Bleeding Disorders:
Current and Future Treatments with Dr. Christina Tarango
Education Session - New Kids on the Block with Dr. Eric Mullins
- 11:50am Break

PROGRAM

12:00pm	Industry Open House
12:40pm	Close breakout rooms/Lunch Break
1:00pm	Industry Open House
1:40pm	Announce winner of special drawing
1:45pm	Education Session - Stop waiting to thrive presented by Novo Nordisk Education Session – Advocating for yourself/OBDC presented by Randi Clites
2:30pm	Break
3:00pm	Believe LTD Science Fair – open to all
4:00pm	Break
4:30pm	Yoga/Stretch with Josh Holder
5:00pm	Cooking Demonstration with Chef Mike
5:45pm	Break to enjoy your dinner!
6:30pm	Family Fun Night Awards Program Talent Show Denny Baker and Arnold Closing remarks - announce winner of raffle
8:00pm	Break-out rooms will stay open as long as people want Young Adults Teens/Crews Nest Women Men Parents Spouses/Significant Others

Sunday, August 1st

12:45pm	Zoom opens for people to network/get acquainted (optional)
1:00pm	Welcome Jeopardy Game presented by BioMarin
2:00pm	Cookie Decorating Contest
3:00pm	Closing remarks - announce winner of raffles

FRIDAY JULY 30 6:45PM PLENARY SESSION

HTC'S: WHAT THEY DO AND HOW THEY ARE FUNDED

SPONSORED BY CASCADE HEMOPHILIA CONSORTIUM

SPEAKER PANEL

Travis Tussing

JD Regional Coordinator, Federal Grants Director

Travis is the Regional Coordinator for the Hemophilia Foundation of Michigan. He is responsible for handling HFM's federal grants and works directly with the HTCs in our region. Before joining our staff, Travis was an estate planning attorney. Travis has worked with the foundation for many years with our camping programs. He enjoys camping, miscellaneous trivia, and spending time with his family.

Stephanie Raymond

Executive Director, Cascade Hemophilia Foundation

Stephanie has been with Cascade since 1996, including 17 years serving as Associate Director. As Executive Director, she guides the daily operations of 13 full- and part-time staff. She has extensive knowledge of the 340B Federal Drug Discount Program. Stephanie also manages the administration of Cascade's multi-million-dollar grant program to 17 Hemophilia Treatment Centers (HTCs) and 7 Hemophilia Foundations located in Michigan, Ohio, and Indiana. Stephanie holds a bachelor's degree in health care administration from Concordia University.

Colleen Joiner, LMSW

Clinical Care Manager, Education and Outreach

Colleen started with the Cascade team in 2016. She attended Michigan State University and then Wayne State University for her Master's in Social Work degree. Colleen has worked with individuals and families living with chronic illness through the span of her career. She began working in the bleeding disorder community in 2001, and currently provides patient insurance navigation, education, and outreach with Cascade. She appreciates working with such caring and resilient group of people.

Stephanie Sibrel, RN

Clinical Care Manager, Education and Outreach

Stephanie joined the Cascade staff in September of 2019 as a Registered Nurse with over 20 years of experience in the hospital and ambulatory setting. She obtained her Bachelor of Science in Nursing from Spring Arbor University. She has an immense passion for the bleeding disorder community having worked as the Nurse Coordinator for the Northwest Ohio Hemophilia Center in Toledo, Ohio. Stephanie loves volunteering in the community and has served at Camp Bold Eagle, on the FAMOHIO Board, and at multiple Northwest Ohio Hemophilia Foundation events.

Amy Dunn, MD

Professor of Pediatrics, Nationwide Children's Hospital/Ohio State University

Amy L. Dunn, MD is a Professor of Pediatrics at Nationwide Children's Hospital/Ohio State University where she is the Director of Pediatric Hematology and directs the Hemophilia Treatment Center. Dr Dunn received her medical degree from Wright State University School of Medicine in Dayton, Ohio and completed her pediatric and pediatric hematology/oncology training at Emory University in Atlanta, Georgia. Dr Dunn is a member of various professional associations including the American Society of Hematology, World Federation of Hemophilia, The International Society of Thrombosis and Hemostasis, the International Pediatric Hemophilia Network, the International Prophylaxis Study Group and the Hemophilia and Thrombosis Research Society (HTRS). She is the Vice-President of the World Federation of Hemophilia, USA. She has served as a reviewer for hematologic journals including Pediatric Blood and Cancer, the Journal of Thrombosis and Haemostasis, Blood and Haemophilia. She has published numerous peer-reviewed articles and has given presentations at national and international medical symposia. Dr Dunn has also received multiple awards, including the US News and World Report Top Doctors, and was the National Hemophilia Foundation Physician of the Year for 2020.

Kristen Peace, BS, RN, Nurse Coordinator, Northwest Ohio Hemophilia Center

Kristen has been a registered nurse for over 13 years, with experience in the hospital, ER, and ambulatory setting. She has specialized in hemostasis and thrombosis care since 2015 when she joined the staff at the Northwest Ohio Hemophilia Center, and in 2019 she transitioned to the Nurse Coordinator role. Kristen is passionate about the care of patients with bleeding disorders and loves being part of the community. Kristen is currently working on her MSN degree with an anticipated graduation date of 2023.

Linda Vo, MSN Licensed Social Worker, The Ohio State University Wexner Medical Center

Linda attended Ohio State University for her undergrad and Master's in social work. Linda started in the field as a school-based mental health counselor working with youth and families and began working with Ohio State University Medical Center's Hemostasis and Thrombosis Center in December 2018. She currently works with adult patients with bleeding disorders, including outreach with Amish patients at Wooster Community Hospital. She assists patients with a multitude of needs including mental health resources, insurance navigation, financial assistance, transition from Children's hospitals, and advocacy and involvement in the bleeding disorder community.

Debbie Shijo, PT, MPT**Physical Therapist, Akron Children's Hospital**

Debbie is a born and raised Buckeye. She received her Bachelor of Science in Exercise Science at the University of Toledo and her Master of Physical Therapy from Chatham College. She is a staff physical therapist at Akron Children's Hospital where she has been employed for 18 years. In addition, for the past 16 years she has had the pleasure of working with a wonderfully collaborative team as one of the physical therapists in the Hemostasis and Thrombosis Center at Akron Children's Hospital. Debbie enjoys spending time working with the Northern Ohio Hemophilia Foundation's Summer Youth Golf Program. During the program she is able to interact with kids affected by bleeding disorders outside of the clinic setting, providing additional education while helping them learn and adapt a lifelong sport.

SATURDAY, JULY 31ST - 4:30PM

YOGA/STRETCH WITH JOSH HOLDER

INSPIRED BY HIS OWN POWERFUL EXPERIENCE WITH YOGA, JOSH BECAME AN INSTRUCTOR TO SHARE HIS PRACTICE WITH AS MANY PEOPLE AS POSSIBLE. WHEREVER YOU MAY BE IN LIFE, FROM TEEN TO SENIOR AND ALL STAGES BETWEEN, WHETHER YOU COME TO PRACTICE IN A CHAIR OR ON THE MAT, WHETHER YOU'RE SEEKING STRENGTH OR HEALING, JOSH CAN SHARE THIS PRACTICE WITH YOU. THE GIFT OF YOGA CHANGED HIS LIFE AND IT THIS CAN BE THE START OF A CHANGE FOR YOU TOO!

DOOR PRIZE DRAWINGS

FRIDAY AT 8:00PM \$25 AMAZON GIFT CARD (2)
SATURDAY AT 11:50AM \$25 AMAZON GIFT CARD
SATURDAY AT 2:30PM \$25 AMAZON GIFT CARD
SATURDAY AT 8:00PM \$25 AMAZON GIFT CARD (2)
SUNDAY AT 2:00PM \$25 AMAZON GIFT CARD
SUNDAY AT 3:00PM \$50 AMAZON GIFT CARD (2)

SPECIAL DRAWING FOR THOSE WHO PARTICIPATE IN
THE INDUSTRY OPEN HOUSE FROM 12-2PM ON SATURDAY
\$25 AMAZON GIFT CARD (2)
\$50 AMAZON GIFT CARD (2)
\$100 AMAZON GIFT CARD (2)

ADDITIONAL DRAWINGS MAY BE HELD THROUGHOUT THE WEEKEND.

YOU MUST BE PRESENT TO WIN.

-9-

GIFT CARDS WILL BE EMAILED A FEW DAYS AFTER THE CONFERENCE ENDS.

Join Zoom Meeting: <https://zoom.us/j/96025979164>

BREAKOUT SESSIONS

Friday July 30- Young Adult Breakout session 8:00 pm **One Stage to the Next: Navigating Life with a Bleeding Disorder**

Sponsored by Takeda

Presented by Jan Martin MSN, RN-BC, CPN, Alumnus CCRN, Senior Clinical Specialist

Jan has 37 years of nursing experience. Prior to coming to Takeda in 2019, Jan's experience includes 22 years in Critical Care and 15 years in the Hemostasis and Thrombosis Center at University Hospitals in Cleveland. Jan has a Hemostasis Nursing Certification from the American Nurses Credentialing Center, is a Certified Pediatric Nurse, and maintains Alumnus Status of her Critical Care (CCRN) certification. Jan was always intrigued by the coagulation cascade as an ICU nurse and ECMO Specialist and is now dedicated to helping improve the life of bleeding and clotting disorder patients. Jan has experience in bleeding/clotting disorder research, coordinating an anti-coagulation program, a young woman with bleeding disorders clinic, as well as a blood conservation program. Jan has presented both nationally and internationally and has been a contributing author of several published journal articles on bleeding and clotting disorders.

Jan will provide education on living independently to help you gain valuable insights into meal planning, understanding insurance and emergency planning so you can focus on what's important: your adult life. With independence comes the power of choice. Jan will also discuss making smart and safe choices. Making informed choices will help keep you healthy and happy as you transition to adulthood and beyond.

Friday July 30- Women's Breakout session 8:00 pm

Emily Murphy, Instructor

Emily is a master healer, artist and intuitive guide. Emily will provide instruction for a fun project while focusing on relaxation and flow.

Saturday, July 31st - 10:15am Plenary Session

Surviving Brain to Thriving Brain: Let's Talk About it

Presented by Debbie de la Riva, LPC, Licensed Professional Counselor

Certified Mental Health First Aid Instructor

This will be a pre-recorded session and Debbie will be available for questions following the presentation. This presentation will cover:

- The mental health impact of prolonged stress
- The nature of the surviving and thriving brain
- The power of thinking and behavioral change
- Evidence-based techniques involved with reclaiming your life

There will be references to the book participants received (The Anxiety First Aid Kit: Quick Tools For Extreme, Uncertain Times)

Saturday, July 31st at 11:05am- Education Breakouts Choose 1

Breakout 1 - Von Willebrand Disease and Rare Bleeding Disorders: Current and Future Treatments

Dr. Cristina Tarango

Associate Professor of Pediatrics

Medical Director of the Hemophilia Treatment Center at Cincinnati Children's Hospital Medical Center

This presentation will cover the basics of blood clotting, von Willebrand disease, and rare factor deficiencies.

Dr. Cristina Tarango is an Associate Professor of Pediatrics and is the Medical Director of the Hemophilia Treatment Center at Cincinnati Children's Hospital Medical Center. She received her medical degree from Stanford University School of Medicine and completed her pediatric training at Yale-New Haven Hospital in New Haven, Connecticut. She did her pediatric hematology/oncology training at UT Southwestern Medical School at Dallas in her home state of Texas. She has faculty at Cincinnati Children's Hospital since 2010. Dr. Tarango is committed to improving the care and outcomes of individuals with bleeding and clotting disorders.

Breakout 2 - New Kids on the Block – New Hemophilia Treatments

Eric Mullins, MD

Research Director, HTC

Cincinnati Children's Hospital Medical Center

Dr. Mullins is an Associate Professor of Pediatrics at Cincinnati Children's Hospital Medical Center and the University of Cincinnati - College of Medicine. He has focused his career on the care of children with coagulation disorders, both bleeding disorders and thrombosis. Dr. Mullins, along with Pediatric Gynecology, founded the Young Women's with Bleeding Disorders Clinic at Cincinnati Children's in 2008 and has had active collaborations with Gynecology since that time. More recently, he has enjoyed collaborating with the Transgender Health Clinic in Adolescent Medicine for care of transgender adolescents and young adults.

Dr. Mullins now has an NIH-funded laboratory research program to investigate the role of coagulation factors in driving neuroinflammation, specifically in the setting of multiple sclerosis. He has found that fibrinolysis is a key step in driving neuroinflammation. His research focuses on novel ways to exploit these findings to intervene in disease processes.

Saturday, July 31st at 1:45- Education Breakouts Choose 1

Breakout 3- Stop Waiting to Thrive

Sponsored by Novo Nordisk

Presented by Judy Doyle

Stop Waiting to Thrive, 6 Principles of Empowerment module was developed by Matthew Barkdull, who is certified in medical family therapy, advanced wellness, and executive coaching. Mr. Barkdull has an MS degree in marriage and family therapy, as well as an MBA. He is also a cancer survivor with severe hemophilia factor IX.

Human beings have this tendency to go through life in what social scientists call autopilot or survival-mode, meaning they often are not truly living, but merely existing and blindly conforming to the current of personal and societal whims. The day-to-day monotony of autopilot behaviors compromises our ability to thrive and find fulfillment. Making excuses is part of being in survival mode. Convincing the mind and the body that it is safer to not take risks, but to stay in one's comfort zone, is seminal to this plight. In other words, it's hard to stop waiting and start really thriving. Our expert, Mr. Barkdull, has 6 principles that may help provide the fuel needed to lift off.

Judy lives in Medina, Ohio and is your local Novo Nordisk Hemophilia Community Liaison, covering Ohio and Indiana. She began her career at Novo in March of 2020, just as COVID was taking hold. While a majority of her time has been virtual, she has taken advantage of every opportunity to attend live events and meetings. Having worked in patient advocacy for over 20 years, she admires the strength and tenacity of the bleeding disorder community. Her passion is connecting with patients and caregivers and is looking forward to meeting you in person soon. Please feel free to reach out and introduce yourself at 216-217-4197.

Breakout 4 -Insurance and Access to Care Updates and Advocacy Tips

Presented by Randi Clites

Randi is the Rare Disease Policy Director for Little Hercules Foundation.

Randi became an advocate for affordable access to healthcare for medically fragile children by leading the parent advisory councils at both Akron Children's Hospital and Ohio's Title V Program - Children with Medical Handicaps - through the Ohio Department of Health. In 2012, she represented Ohio as a Family Scholar for the Association of Maternal and Child Health Program. Randi helped develop an annual Statehouse Day in 2008 for the hemophilia community that has engaged hundreds of families in State Advocacy. She was the advocacy coordinator for a coalition of providers, patients, and non-profits serving bleeding disorders patients for over 10 years.

Randi took her passion of working on policy to public office, serving as State Representative for the 75th Ohio House District during the 133rd General Assembly. She passed bills to establish a Rare Disease Advisory Council and protect vulnerable patients in Ohio. Randi comes with a lot of non-profit experience in training patients and parents to advocate for access to treatment.

Randi is a fierce advocate for patients and families with rare disorders. Her only child Colton, now 18, was born with severe hemophilia and later diagnosed with leukemia at 15 months old. Randi lives in Northeast Ohio with her husband Matt, son Colton, and their three dogs. Randi earned her degree in Business Administration with a minor in Political Science from Hiram College.

INDUSTRY OPEN HOUSE - SATURDAY, NOON TO 1:40PM

JOIN US FOR AN OPPORTUNITY TO MEET WITH OUR INDUSTRY PARTNERS WHO HAVE SUPPORTED THE CONFERENCE THIS YEAR. WE WILL BE USING ZOOM BREAKOUT ROOMS TO MEET WITH EACH OF THE COMPANIES FOR A BRIEF PERIOD OF TIME. YOU WILL LOG IN TO THE PROGRAM USING THE SAME LINK AS THE REST OF THE WEEKEND. MORE DETAILS WILL BE SHARED THAT DAY. FAMILIES WHO PARTICIPATE IN THE ENTIRE PROGRAM WILL BE ENTERED INTO A SPECIAL DOOR PRIZE DRAWING (SEE PAGE 9).



ATTENTION TEENS! (13-17 YEAR OLDS ONLY)
JOIN US FOR AN ACTION PACKED SCHEDULE
THROUGHOUT THE EDUCATION WEEKEND:

FRIDAY, JULY 30

8-8:50PM - CATCHING UP!

8:50-10:30PM - MYSTERY ESCAPE ROOM

10:30PM-12:00AM - GAMES

SATURDAY, JULY 31

8-9:00PM - MARSHMALLOW CREATIONS

9-10:00PM - MAKE MY LEGO

10-11:00PM - PILLOW CASE METAPHORS

11:00PM-12:00AM - GAMES



ATTENTION LADIES!
JOIN US FOR AN ART ACTIVITY IN
THE WOMEN'S COMFORT ROOM
ON FRIDAY AT 8:00PM

DENNY BAKER, VENTRILOQUIST

As a 10-year-old, Denny Baker first got a taste of the power of ventriloquism after a trip to the Vent Haven Museum. Seeing hundreds of ventriloquist artifacts and dummies, Denny decided to tap into the entertainment form and discovered his talent for the unusual and unique art form. Denny performed his first show at 10 years old, and he continued to pursue his love of entertainment through his involvement in the glee club at Elder High School. Thanks to the music teacher, he and one of his “friends”, a ventriloquist puppet, had a spot in every glee club performance, bringing audience members on stage, bantering with a spectator and after some coaxing, finally convincing his puppet to sing a song. Denny went on to win a number of junior competition awards, including several at the International Ventriloquist convention, as well as a 12-week city-wide talent search.

In his adulthood, Denny lives out another lifelong passion as a professional firefighter. He has held positions at Delhi Township, Middletown, Ohio, and is currently a Fire Lieutenant and paramedic with the Cincinnati Fire Department where he’s been since 1996.



www.DennyBaker.com

Put on your lab coat, approach the microscope, and enter
BELIEVE LIMITED'S SCIENCE FAIR!

Guided by virtual hosts Dr. Morales and Patrick James Lynch, the Science Fair is a family-friendly (and fun!) way to learn the fundamental bleeding disorders science of today, the breakthrough science that brought us here, and the cutting-edge science guiding where we go next. The Science Fair explores the treatments for and science behind hemophilia, vWD, rare factor deficiencies, women with bleeding disorders, and so much more—including the exciting science behind gene transfer!
Founding sponsor: Spark Therapeutics.

**3:00PM
SATURDAY**

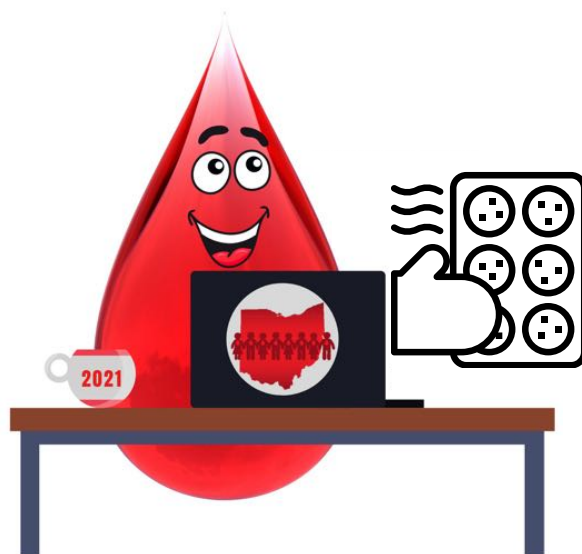


**JOIN US ON SATURDAY AT
5:00PM FOR A
COOKING
DEMONSTRATION!**

**CREAMY DREAMY
MAC & CHEESE**



**JOIN US ON SUNDAY AT
2:00PM FOR A
COOKIE DECORATING
CONTEST!**



OBDC & CHAPTER UPDATE



Joy Linder
Southwest Ohio Hemophilia Foundation
joy@swohf.org
937-298-8000
www.swohg.org

The Southwestern Ohio Hemophilia Foundation partners with the Hemophilia Treatment Center at Dayton Children's Medical Center to provide services for the bleeding disorders community in the Dayton area and 12 surrounding counties. We provide funding for a Summer Camp, An Annual Family Fest...which is a weekend Retreat to increase families knowledge of bleeding disorders and instruct them on managing issues related to the disorders. Additionally, SWOHF publishes a quarterly newsletter Factor Notes that provides relevant information and chapter activities. We have a website www.swohf.org that is updated regularly to advance issues of the community. We provide Emergency Assistance funds, travel grants for educational purposes, Personal Medical Identification bracelets and work with Industry Partners to assist the community in receiving the latest advances in medical treatment.



Helen Lamping
Tri-State Bleeding Disorder Foundation
Helen@TSBDF.com
513-961-4366
www.TSBDF.com

The Tri-State Bleeding Disorder Foundation is committed to helping support and care for those individuals within our community affected by a Bleeding Disorder.

TSBDF's goals include:

- Providing programs essential for the physical, psychological and financial health of those with bleeding disorders.
- Assisting those with bleeding disorders in striving to attain their fullest potential.
- To increase community awareness of bleeding disorder issues through education and advocacy.

With a long history of providing programs for bleeding disorder patients, as well as board members with professional knowledge and personal experience with bleeding disorders, TSBDF has established a reputation as a strong support system for the bleeding disorder community. TSBDF seeks input from families of patients and professionals in the field of hematology to guide program decisions.



www.ohiobdc.org
or talk to your local Chapter Executive Director
about getting involved.

The Ohio Bleeding Disorder Council is comprised of the 8 Hemophilia Treatment Centers and 5 Chapters in Ohio. The mission of OBDC is to ensure and enhance the quality and accessibility of comprehensive care and services for children and adults with hemophilia and related bleeding disorders through information sharing, public education and advocacy. Each year, the Ohio Bleeding Disorders Council hosts Statehouse Day, where people affected by a bleeding disorder get to meet their state elected officials and voice their concerns about issues important to the Ohio bleeding disorders community. Due to the Pandemic we hosted 6 virtual meetings with Legislators across the State this fall. If you're interested in learning more about OBDC, please check out our website at www.ohiobdc.org or you can talk to your local Chapter Executive Director about getting involved.

OBDC & CHAPTER UPDATES



Wendy Perkins
Central Ohio Chapter
wperkins@hemophilia.org
614-902-3965
nhfcentralohio.org

The Central Ohio Chapter of the National Hemophilia Foundation is dedicated to providing education, advocacy, and support programs for people with bleeding and clotting disorders, and to driving innovations that lead to a better quality of life for our consumers. We were founded out of a need to raise awareness for voices not heard. We have continued to make a difference with the help of our donors and volunteers that make our mission possible.



Tanya Ricchi
Northern Ohio Hemophilia Foundation
tanya@nohf.org
216-834-0051
www.nohf.org

At the NOHF, we aim to enhance the quality of life for people with genetic bleeding disorders and their families, through advocacy, education, research and other constituency services. Over the years, NOHF has recognized and adapted its services to meet the equally challenging and devastation psychological and social needs of caregivers, siblings of a child with a bleeding disorder, as well as of the child him/herself.

The entire family is affected by the bleeding disorder physically, emotionally, and financially. With over 60 years of serving the bleeding disorders community, we provide many programs and services to people affected by bleeding disorders. We partner with Hemophilia Treatment Centers, other agencies, and medical professionals to provide programs and services unique to those with bleeding disorders to best meet their needs.



Carla Wells
Northwest Ohio Hemophilia Foundation
carla@nwohemophilia.org
419-291-5882
www.nwohemophilia.org

For more than 55 years, The Northwest Ohio Hemophilia Foundation has assisted individuals and families affected by bleeding disorders. Through family networking events, sending youth to a specialized camp, maintaining a family crisis fund, providing medical identifications, facilitating educational workshops, and advocating at the local, state, and national level on critical legislation, our Foundation is committed to helping people manage their condition. Currently we serve more than 2000 individuals within the 22 counties in Northwest Ohio that we serve.

Our Foundation is run by an all-volunteer Board of Directors that includes affected individuals and professionals from Northwest Ohio. We partner with industry and other chapters to ensure that we provide the best service to our members.



A Trusted Partner in Your Circle of Care

- Non-profit pharmacy dedicated to respond to the needs of persons affected by bleeding disorders
- A 340B covered entity offering among the lowest prices for factor available
- Governed by a volunteer board of directors from the bleeding disorders community
- Returns all excess revenues to the community for support of patient services and HTC programs

For more information visit us at cascadehc.org

Judy Doyle

Patient advocate

About Judy

Judy is a Novo Nordisk Hemophilia Community Liaison with 18 years of experience supporting those with bleeding disorders. She loves the passion of the hemophilia community to get things done and not let things stand in their way.

Hobbies

- Gardening
- Making jewelry

"I became a liaison because of my desire to help people, specifically those with rare disorders."

Connect with Judy

JDDL@novonordisk.com
(216) 217-4197

Hemophilia Community Liaison





Exploring the science behind gene therapy research

Gene therapy research has the potential to bring an entirely new option to people with specific genetic conditions. Many gene therapies are in clinical trials to evaluate the possible risks and benefits for a range of conditions, including hemophilia. HemDifferently is here with gene therapy education, providing accurate information on the basics and beyond.

What questions do you have? Get them answered. Explore gene therapy at **HemDifferently.com**

No gene therapies for hemophilia have been approved for use or determined to be safe or effective.

BiOMARIN

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Specialty Pharmacy. Experienced Care.

At Accredo, we understand it can be difficult to live with a chronic or complex illness and subsequent care.

As one of the nation's leading and largest providers of specialty pharmaceuticals, our dedicated therapy teams work diligently to coordinate solutions for the challenges of those living with a bleeding disorder.

With accurate and timely delivery of medication, as well as expert guidance through ongoing therapy directives, you can trust Accredo to provide experienced care.

Contact us
for more
information.

Patients call: 866.712.5200
Physician offices call: 866.712.5007

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accredo

Akron Children's Hospital treats every child as if they were our own.



It's our care for children with conditions such as bleeding disorders that sets us apart – from education and surgery planning to a smooth transition from pediatric to adult medical care. It's family-centered care, and what every child deserves.

For more information about the 340B Factor Program, call JD at 330-543-3513 or toll-free 1-800-262-0333 ext 33513.

<http://www.akronchildrens.org/departments/Hemostasis-and-Thrombosis-Center.html>

The 340B Factor Program is proud to support the Akron Children's Hospital Hemostasis and Thrombosis Center's mission of providing exceptional comprehensive care for all bleeding disorders.



Connected to milestones.

Life with a rare blood disorder shouldn't be defined by limits. Through research, partnerships, and support, we're focused on making more possible for you and the people you love.



Let's connect.
rareblooddisorders.com
1-855-SOZHEME

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SANOFI GENZYME



Homecare Factor Program

It takes a team for best patient outcomes!

The Factor Care Team consists of your child's Hemophilia Treatment Center physician and primary nurse, a Homecare factor care coordinator, a Homecare infusion pharmacist and a social worker.

Working directly with you and your child, the Factor Care Team provides support and care to help your child be a "kid", while safely and effectively treating their hemophilia.

To learn more visit NationwideChildrens.org/Homecare-Factor or call (614) 355-1100/(800) 466-2727, Monday thru Friday, 8 a.m. - 5 p.m. and ask to speak with the Factor Care Coordinator.



(500004 10/12)



Jivi® Extension Study Results

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Coagulation Factor IX (Recombinant), Albumin Fusion Protein

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IDU-0350-JUL19

DEDICATION AND PERSONAL SUPPORT



Introducing your Pfizer Patient Affairs Liaison, a professional dedicated to serving the rare disease community by connecting patients, caregivers, and patient advocacy organizations with Pfizer Rare Disease tools and resources. A Patient Affairs Liaison's work is guided by the principles of **compassion, commitment, and connection.**

Chris Liddell

Southern OH, MI, KY, IN

I'm here to:

- Provide compassion by understanding the needs of patients, caregivers, and patient advocacy organizations and serving as a point of contact for questions they may have
- Maintain commitment by educating patients and caregivers about Pfizer Rare Disease patient support resources
- Facilitate connection by providing educational programs that bring patients, caregivers, and patient advocacy organizations together to share experiences and support advocacy for their communities

"I've worked in rare disease for 15 years, and I have experience collaborating with and advocating for different members of this community."



To get in touch with Chris:

248-660-7384

✉ chris.liddell@pfizer.com

Pfizer Rare Disease



Strength, Support and Community
for People Living with Bleeding Disorders

Factor My Way is a robust patient support program from Octapharma designed for people living with hemophilia A and von Willebrand disease, and for those who care for them. We spoke with you and we listened. The insights we gathered form the foundation of our bleeding disorders patient support program. Built around your needs, Factor My Way includes resources for patients and caregivers, support for those navigating care, reliable educational materials, and uplifting community connection.



Join Today!
factormyway.com/join

Member benefits include:

- ✓ Financial assistance, including free trials and co-pay assistance for eligible patients
- ✓ A dedicated, local Factor My Way Patient Experience Manager, a specialist in dealing with bleeding disorders
- ✓ Access to a wide range of digital programs and events
- ✓ On-demand access to practical and informative educational resources ... and lots more. Membership in Factor My Way is complimentary. Join the program at factormyway.com/join, or call 1-855-498-4260

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octapharma

Important facts about VONVENDI®:

This leaflet summarizes important information about VONVENDI. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider.

vonvendi
(von Willebrand factor
(Recombinant))

What is VONVENDI?

VONVENDI is a recombinant medicine used to replace low levels or not properly working von Willebrand factor in people with von Willebrand disease. Von Willebrand disease is an inherited bleeding disorder in which blood does not clot normally. VONVENDI is used in adults (age 18 years and older) diagnosed with von Willebrand disease to:

- Treat and control bleeding episodes
- Prevent excessive bleeding during and after surgery

Who should not use VONVENDI?

You should not use VONVENDI if you:

- Are allergic to any ingredients in VONVENDI.
- Are allergic to mice or hamsters.

Tell your healthcare provider if you are pregnant or breastfeeding because VONVENDI may not be right for you.

What should I tell my healthcare provider before I use VONVENDI?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if VONVENDI passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if VONVENDI can harm your unborn baby.
- Have been told that you have inhibitors to von Willebrand factor (because VONVENDI may not work for you).
- Have been told that you have inhibitors to blood coagulation factor VIII.

What is the most important information I need to know about VONVENDI?

VONVENDI can cause blood clots particularly in patients with known risk factors for blood clots. Discuss this risk with your healthcare provider.

You can have allergic reactions to VONVENDI. Symptoms may include generalized itching; rash or hives; rapid swelling of the skin or mucous membranes; chest pain or tightness; tightness of the throat; low blood pressure; shock; drowsiness; nausea; vomiting; tingling, pricking, burning, or numbness of the skin; restlessness; wheezing and/or difficulty breathing; lightheadedness; dizziness; or fainting. If symptoms occur, stop using VONVENDI immediately and get emergency treatment right away.

Your body can form inhibitors to von Willebrand factor or factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, they may stop VONVENDI or FVIII from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to von Willebrand factor or factor VIII.

What are the possible side effects of VONVENDI?

Side effects that have been reported with VONVENDI include: nausea, vomiting, tingling or burning at infusion site, chest discomfort, dizziness, hot flashes, itching, high blood pressure, muscle twitching, unusual taste, blood clots and increased heart rate. These are not all the possible side effects with VONVENDI. You can ask your healthcare provider for information that is written for healthcare professionals.

Tell your healthcare provider about any side effects that bother you or do not go away.

What else should I know about VONVENDI and von Willebrand Disease?

Consult with your healthcare provider to make sure you are carefully monitored with blood tests to measure levels of von Willebrand factor and factor VIII so they are right for you. You may infuse VONVENDI at a hemophilia treatment center (HTC), at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or HTC. Many people with von Willebrand disease learn to infuse VONVENDI by themselves or with the help of a family member.

Call your healthcare provider right away if your bleeding does not stop after taking VONVENDI.

Medicines are sometimes prescribed for purposes other than those listed here. Do not use VONVENDI for a condition for which it is not prescribed. Do not share VONVENDI with other people, even if they have the same symptoms that you have.

The risk information provided here is not comprehensive. To learn more, talk with your healthcare provider or pharmacist about Vonvendi. The FDA approved product labeling can be found at http://www.shirecontent.com/PDFs/VONVENDI_USA_ENG.pdf or call 1-800-828-2088.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

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MY DECIDING FACTOR:

Making time for what matters most.

vonvendi
von Willebrand factor
(Recombinant)

Erica
Surprise, AZ
Diagnosed with VWD in 1990

Are you ready to ask about
VONVENDI for your VWD?
Visit VONVENDI.com to
learn more.

As an adult living with von Willebrand disease (VWD), you may share a bleeding disorder with others, but you have your own life, and your own needs. You may also have your own Deciding Factor—something that drives you to talk to your healthcare provider about finding a treatment that's right for you. For Erica, it was that her frequent bleeding episodes were taking time away from things that mattered most to her. She talked with her healthcare provider, and together they decided that VONVENDI® von Willebrand (Recombinant) was right for Erica's VWD.

VONVENDI

- Is used in adults (age 18 and older) diagnosed with VWD to treat and control bleeding episodes and prevent excessive bleeding during and after surgery
- Is the first and only recombinant von Willebrand factor (vWF), meaning it is manufactured without human plasma or blood
- May be used with or without a recombinant factor VII (rFVII), as instructed by your healthcare provider

VONVENDI Important Risk Information

Who should not use VONVENDI?

You should not use VONVENDI if you:

- Are allergic to any ingredients in VONVENDI.
- Are allergic to mice or hamsters.

Tell your healthcare provider if you are pregnant or breastfeeding because VONVENDI may not be right for you.

Please see additional Important Risk Information below.

Important Risk Information (continued)

How should I use VONVENDI?

Your first dose of VONVENDI for each bleeding episode may be administered with a recombinant factor VII as instructed by your healthcare provider. Your healthcare provider will instruct you whether additional doses of VONVENDI with or without recombinant factor VII are needed.

What should I tell my healthcare provider before I use VONVENDI?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if VONVENDI passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if VONVENDI can harm your unborn baby.
- Have been told that you have inhibitors to von Willebrand factor (because VONVENDI may not work for you).
- Have been told that you have inhibitors to blood coagulation factor VIII.

What else should I know about VONVENDI and von Willebrand disease?

Your body can form inhibitors to von Willebrand factor or factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop VONVENDI or factor VIII from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to von Willebrand factor or factor VIII.

What are the possible side effects of VONVENDI?

You can have an allergic reaction to VONVENDI.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Side effects that have been reported with VONVENDI include: nausea, vomiting, tingling or burning at infusion site, chest discomfort, dizziness, hot flashes, itching, high blood pressure, muscle twitching, unusual taste, blood clots and increased heart rate.

Tell your healthcare provider about any side effects that bother you or do not go away.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see VONVENDI Consumer Brief Summary on the following page and talk to your healthcare provider.



MECHANICAL

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