

SPECIAL EDITION: 2024 PATIENT CONFERENCE

From the Executive Director:

Wow! The 2024 National Type 3/ Severe VWD Conference was one for the history books! Who would think that in the wee hours of arrival day for our attendees there would be a global communications outage that grounded all the airlines? Needless to say, we were off to a rough start...

By the end of the day on Friday, it looked as though about half of our registered attendees were not going to make it to the conference – including some key Faculty members. But our members are fantastic, and those who made it in were ready to roll with the punches.

We switched gears and adjusted the agenda each day based on available Faculty, and the in-house Faculty rose to the changes admirably. This year we had many first-time Staff members, and they did an outstanding job adapting to whatever needed to get done. Everyone pitched in and we ended up having a fantastic conference! Even with the travel challenges, we had 36 first-time attendees at the Conference, and six new Faculty Members joined the team.

Read on for more details of what happened, and what we have planned for future activities.

And don't forget to check out our website for lots more fun photos of this year's conference!

HERO AWARD

At the 2024 Conference the Foundation gave out its first award – the Hero Award was presented to Dr. Robert Montgomery recognizing his endless dedication to patients and their families living with VWD. Dr. Montgomery has participated in every one of the eight conferences we have held, and whenever asked to jump in on a Foundation project he is there in a heartbeat. From advising on the sVWD Patient Registry to his participation on both our Medical and Scientific Advisory Board and International Expert Opinion Panel on sVWD, Dr. Montgomery shares his vast knowledge, constantly striving to improve management for our patients with sVWD. Dr. Montgomery, you truly are our Hero!



and live-streamed Dr. Walsh on Sunday morning. He presented case studies to illuminate the variety of concerns and approaches to consider when a sVWD is facing cardiac or surgical issues, followed by a robust Q&A period.

Alfredo Narvaez presented on *PTSD and Medical Trauma*, then our social work team held a group discussion, taking time to process what could be triggering content. Breakouts included “Family Planning,” “Dealing with Chronic Pain” and “Keeping the Generations Connected.”

SESSIONS

Per patient request, we added a number of new sessions this year. Of note was **Dr. Chris Walsh's Cardiac and Surgical Considerations**. After multiple flight cancellations we quickly pivoted (with the help of our tech-savvy genetic counselors)



MEMBER LOUNGE

Every night from 8 PM to midnight, Polo D was transformed into our new Member Lounge with comfy chairs and warm lighting. It was well utilized each evening as Members gathered to connect!

SENSORY EXPLORATION

On Sunday afternoon, attendees had two hours to explore how engaging our senses can help reduce stress and anxiety – and overall just make us happy! Activity choices were plentiful and it was wonderful to see attendees finding their “happy place” and jumping in on the activities. To learn more about how sensory awareness can be beneficial, [CLICK HERE](#)

The exploration included:

SIGHT Spin Art and Collaging

SMELL Aromatherapy

HEARING Jam session and drum circle

TOUCH Self-massage and singing bowls

TASTE Make your own trail mix and power smoothies



PRIVATE INFUSION CONSULTATIONS

In another great idea from a Member, our infusion nurses offered 20-minute private consultations to discuss patients’ and families’ questions about infusing.

So happy to hear from Members who met with the nurses, then went home and successfully put the tips they had learned into practice!



ENTERTAINMENT

Music, face painting, fairy hair, juggling show, fire dancer, karaoke, trivia, dancing – and did we mention the petting zoo? There were special activities for our younger members, a field trip to Lion Country Safari, Games Master, Magic Show and a bracelet-making Girl Talk event with Dr. Krishnan.



COMING UP

VIRTUAL EVENT
MONTHLY MEMBER MEETUP
THURSDAY, AUGUST 22 at 8:00PM ET

[REGISTER HERE](#)

VIRTUAL EVENT
BOOK MOVIE CLUB: OPPENHEIMER
WEDNESDAY, SEPTEMBER 4
at 8:00PM ET

We’re shaking things up with a movie discussion! *Oppenheimer* follows the life of J. Robert Oppenheimer, the American theoretical physicist who helped develop the first nuclear weapons during World War II. The film won seven Oscars including Best Picture, Best Director, Best Actor and Best Supporting Actor.



[REGISTER HERE](#)

LOOKING AHEAD

Before the end of the year, we will be providing a series of educational sessions via Zoom including an insurance drop-in, evening with Physical Therapy and a much-requested Research Night. Stay tuned for upcoming dates!

For those of you who live in the New England area, we hope to see you at the First Annual VWD Connect Golf Tournament, organized by our new Members, the Roches. From the talk at the Conference, it sounds like Members will be well represented! For more info, click on the graphic below.

Golf
FIRST ANNUAL
TOURNAMENT
benefiting
VWDCONNECT
FOUNDATION

FRIDAY
OCTOBER
11th

Shining Rock Golf Club
91 Clubhouse Lane
Northbridge, MA
Registration opens at 7am

8:30
AM
SHOTGUN
START

VWD CONNECT FOUNDATION ANNOUNCES THE
**2025 U.S. NATIONAL TYPE 3/SEVERE
VON WILLEBRAND DISEASE CONFERENCE**

VWDCONNECT
FOUNDATION

JULY 18-21, 2025
WEST PALM BEACH MARRIOTT • FLORIDA



ROCHE/GENENTECH, in partnership with **IQVIA**, are seeking to better understand patient, family, and caregiver experiences with von Willebrand disease Type III through a 75-minute one-off video or telephone interview with eligible participants. The findings from this study can potentially contribute to literature on this disease. For more information click [HERE](#)

TAKEDA is sponsoring a study that will begin enrolling for a Phase 3, Prospective, Open-label, Uncontrolled, Multicenter Study on Efficacy and Safety of Prophylaxis With rVWF in Children Diagnosed with Severe Von Willebrand Disease. For more information click [HERE](#)

NEW YORK BLOOD CENTER ENTERPRISES is involved in a research study actively recruiting individuals with bleeding disorders. Eligible participants will be asked to donate samples of their blood. The purpose of this study is to better understand antibody therapy that can address blood clot formation through the examination of source plasma collected from donor blood. Eligible participants for the study would be individuals with a reported bleeding disorder willing to donate blood for research purposes. For more info, click [HERE](#) to email Stephanie Dormesy.

THE AMERICAN THROMBOSIS AND HEMOSTASIS NETWORK (ATHN) sponsors the ATHNdataset, a large set of de-identified data contributed by persons with blood disorders in the United States. The health information that makes up the ATHNdataset is helping us gain a better understanding of blood disorders so that together, we can transform care and improve lives. Ask your provider to include your data in the ATHNdataset! To learn more, click [HERE](#) to see the ATHNdataset Brochure.

VWD CONNECT FOUNDATION is recruiting severe Von Willebrand Disease patients to enroll in the Severe Von Willebrand Disease (sVWD) Patient Registry. This is your opportunity to have your voice heard! For more information, click [HERE](#)

VEGA THERAPEUTICS, INC. is sponsoring a VWD Clinical Trial that is now enrolling for the VIVID 2 Study (NCT# 05776069) of a new drug called VEGA039 as a single subcutaneous administration for Von Willebrand patients who are symptomatic, ages 18-60 years old. Interested in learning more? Click [HERE](#) or contact your provider.

COMMUNITY CORNER

Behind everything the Foundation does is our community of supporters that make our connections possible. Click on the logos below to learn more about our wonderful sponsors!

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