

## State of the Foundation Event Highlights a Successful 2024 and Exciting 2025 Initiatives

On the last Thursday evening in January, the VWD Connect community gathered for what has become a Foundation tradition: the annual State of the Foundation address. The Zoom event was alive with the energy of a new year as Foundation Members and their loved ones, plus Foundation Faculty and Staff, tuned in to reconnect as a community.

Jeanette Cesta, Founder and Executive Director, introduced 2025's theme as *Building Up*, although "catching up" may have been more appropriate! After all, 2024 was a big year for VWD Connect:

### LETTER FROM THE EDITOR:

*What's Behind Door 25?*  
see page 6

### FOR OUR 2024 HIGHLIGHT REEL, CLICK ON THE PHOTOS AT RIGHT

With the announcement of a new initiative, debut of first-time annual events, and a year full of new connections made within the bleeding disorder community, 2024 certainly gave us plenty to *Build Up* this coming year... and plenty of ways for you to be a part of it!

### 2025 VISION BOARD

**MEMBERSHIP** Starting 2025, the Foundation is adopting the International Consensus Panel's definition of severe VWD as our new membership eligibility criteria. We are proud to have been able to sponsor such an impactful project and to follow the guidance of our experts. Please [CLICK HERE](#) to see the requirements on our updated website page.

*continues on page 3*



**JULY** Eighth National Severe VWD Conference



**OCTOBER** Inaugural Golf Tournament benefiting the Foundation



**NOVEMBER** Inaugural Provider Education Workshop Weekend



**DECEMBER** Poster presentation at ASH Conference

# FEBRUARY RESOURCES

## FEBRUARY 1-7 NATIONAL PATIENT RECOGNITION WEEK

This is a week designed to encourage healthcare providers focus on and celebrate their patients. Let's celebrate ourselves and each other by having a fun, cozy evening together playing trivia on Monday, February 17! [CLICK HERE](#) to register.

## FEBRUARY 3 SIMONE WEIL'S BIRTHDAY

An early 1900s French philosopher, Weil wrestled with health concerns during her brief but vibrant life. Get a taste of her writing with quotes taken from her book "Gravity and Grace" in the Letter from the Editor.

## FEBRUARY 9 NATIONAL DEVELOP ALTERNATIVE VICES DAY

Let this holiday inspire you to survey your current vices, or unhealthy habits, and see if you can make any swaps that might not be perfectly "good" but certainly less bad!

A powerful place we can all start is with our own thinking. Negative self-talk is like a vice with superpowers: when we engage in it, we become more vulnerable to the pull of all the other vices. Slowing down and being intentional about our self-talk (what we say and what we choose to listen to) can be uncomfortable. In the spirit of this holiday, let go of any expectations of what positive self-talk is supposed to be, and try using neutral affirmations on the following page to ground yourself. Now at least when you indulge in all the other vices, you'll be doing so mindfully!

[CLICK HERE](#) to learn more about the science of automatic thinking and the power of our own self-talk.



## FEBRUARY 14 WORLD SOUND HEALING DAY

Those of you who attended our 2024 summer conference or 2023 Mental Health Workshop may recall wellness sessions showcasing the healing power of sound. Remember those drum circles and singing bowls?

If this resonated with you, or if you just want to try something new, [CLICK HERE](#) to learn how to participate in the 23rd annual World Sound Healing Day virtual event. Join voices with people worldwide in a sonic expression of love.

## FEBRUARY 15 ALEX BORSTEIN'S BIRTHDAY

Happy birthday to the woman behind the voice of Lois Griffin on *Family Guy* (and two-time Emmy winner for *The Marvelous Mrs. Maisel*), who is also a long-time public advocate for those with bleeding disorders, including VWD!

## FEBRUARY 16 WORLD WHALE DAY

Many species of whales are incredible deep divers. Turns out, their blood is a key part of what makes them able to accomplish these extraordinary feats with ease – whales have twice the amount of hemoglobin in their blood as we do! [CLICK HERE](#) to learn more.

## FEBRUARY 28 RARE DISEASE DAY

Longtime Members the Schwartz-Newton family got a head start on celebrating 2025 in a creative way – check out their new license plate! [CLICK HERE](#) to read the Member Spotlight in the October 2024 issue to learn more about Joel, Margo, and Oliver!

## NEW: PROVIDER PARTNERSHIP INITIATIVE

Knowing what the Foundation is now, imagine the energy of the days right after that very first patient conference in 2017. The world was hopeful, and we all made new friends, so of course – we did it again! After the first Provider Education Workshop last year in West Palm Beach, the air was full of the same mix of Florida humidity and a buzzing sense of potential (or were those just mosquitoes?), so of course we're not only doing it again, but doing it bigger and better.

The Provider Partnership Initiative will include:

**MENTAL WELLNESS** For members who attended our Mental Health Workshop weekend in 2023, get ready for more! This year, the Foundation intends to expand and fortify our mental wellness programming. We strongly believe that the body and mind are connected, and to care for one you must care for the other as well. From sessions about medical PTSD to grounding activities at in-person events, our Mental Wellness program will teach ways to incorporate caring for our mental and spiritual selves while balancing the

unique physical health needs of having a body with a severe VWD.

**2025 U.S. NATIONAL SEVERE VWD PATIENT CONFERENCE** July 18-21 at the West Palm Beach Marriott. Registration will be open by the end of February – make sure to register as early as possible to have maximum flexibility with hotels rooms and accommodations.

Happy 2025, and let's get to building! •



# VOLUNTEER OPPORTUNITIES

Message us on Facebook or send us an **EMAIL**

## PATIENT ADVISORY BOARD

We are creating a conference-focused Patient Advisory Board to help guide us in planning curriculum content and other activities.

Reach out if you would like to be included on the board or have any specific feedback you'd like your peers to address.

## NEW FOUNDATION WEBSITE

In February, the Foundation's re-vamped website will be ready for rounds of testing...which means we will need guinea pigs... and since few if any guinea pigs know how to use the internet...we will need you!

Help us build our digital presence by volunteering to be a website tester.

## WELCOME COMMITTEE

Under the leadership of our Board of Directors' Patient Representative Jan Golec, we are assembling a Welcome Committee to help first-time conference attendees feel comfortable and open to having the best VWD Connect experience possible!

If you have attended at least four prior conferences and would like to volunteer, please **CLICK HERE** to reach out to Jan directly. See you in July!

# Sherry Herman-Hilker

## How did you connect with the Foundation?

I am a physical therapist at Michigan Medicine at The University of Michigan. I work part-time in outpatient developmental pediatrics and the rest of the time in the Hemophilia and Coagulation Disorders Program. I was first invited to participate as faculty for the VWD Connect Conference when it was virtual during the pandemic. It wasn't until I attended in person for the first time in 2022 that I really experienced what it is all about.

## What are some interesting things about where you live?

I have lived in Michigan essentially all of my life and although I love to visit other places, I really can't imagine living anywhere else. My home is near Ann Arbor, Michigan and I appreciate the excitement of the college town where there is always something fun to do. I am especially drawn to the Great Lakes and feel very lucky that it is just a short drive to some of the most beautiful places on earth.



## What do you do for fun?

I enjoy spending time with my family and friends, traveling, hiking, taking long walks. I find wandering around new cities and exploring 'off the beaten path' especially fun. I am equally happy with an outing to a new place or a quiet afternoon chatting with friends or reading a good book.

## How did you get started doing PT specifically for bleeding disorders?

I was working as a pediatric physical therapist at Mott Children's Hospital in 1995 when a four hour per week position was posted in the Coagulation Disorders Program. Before that I had only ever taken care of one person with a bleeding disorder.



Skiing with her husband in Ann Arbor

I was intrigued, applied, and was offered the position. At the time I was hired primarily to collect joint range of motion data for people with bleeding disorders. It quickly became clear that there was a much larger role for

a physical therapist in the clinic. Over time my position grew and today I spend most of my work time in the bleeding disorders program.

## How do you think having that focus has changed your practice versus seeing a general population?

Working within the bleeding disorders community has been an exciting professional challenge for me since day one. There is something new to learn every single day. Focusing on supporting the physical therapy needs of people with bleeding disorders has allowed me to participate in lifespan care for many individuals. It is an absolute privilege to be able to consult with people over the long term. This provides the opportunity to have a deeper understanding of the implications of a bleeding disorder on an individual's life and what will benefit each person. The long-term relationships are unique, and I can honestly say many of my greatest teachers have been those who live every day with a bleeding disorder.

## What is the most satisfying thing about your job? What is the most challenging?

I honestly can't think of one "most satisfying thing" about my job. I love it – all of it. From the day to day interactions with people with bleeding disorders, my coworkers, and the larger bleeding disorders community – to the academic challenges

– the constantly changing and expanding science of the medical care – I find it all fulfilling. It is incredibly compelling and I am so grateful that the opportunity that was presented to me years ago set the trajectory for a career I couldn't have even imagined. The challenge to “keep up” is real – and the learning curve can be steep – but fortunately I have many resources that are helpful along the way.

### What is something about physical therapy that you wish everyone knew?

When it comes to physical therapists in the bleeding disorders community specifically—we are a pretty “tight knit” group. We do a lot of collaborating behind the scenes to try to be sure that we are up-to-date and well prepared to offer the best care and support to our patients. Because bleeding disorders such as sVWD and hemophilia are rare, it isn't surprising that many physical therapists who don't work in Hemophilia Treatment Centers may not be familiar with these conditions. I hope that folks with bleeding disorders know that there are resources available to support community

therapists – no matter where they receive their physical therapy care – and letting their therapists know about their bleeding disorder is important.

### Since you missed last conference due to travel issues, are you planning to come back this year and if so what are you most excited for?

I was very disappointed when cancelled flights prevented me from participating in the conference in July 2024. I hope to be able to return this summer! What I am most excited for is the opportunity to sit and talk again with people living with sVWD --exchanging ideas and experiences. I learn something new from every conversation.

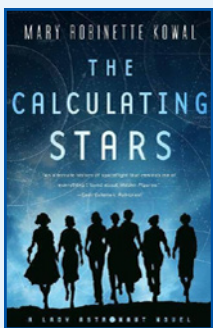
*Sherry will be joining our Monthly Member Meet-up this month (see below) for an Educational Session on PT. Come hear her speak and have your questions answered during the Q&A discussion section! •*



Interested in telling your story?  
Send us an **EMAIL** for more information.

#### VIRTUAL EVENT BOOK CLUB:

**THE CALCULATING STARS**  
WEDNESDAY, FEBRUARY 5  
8:00PM EST



In 1952, pilot and mathematician Elma York and her husband witness an extinction-level meteorite strike which

leads to a radically accelerated effort to colonize space.  
By Mary Kowal.

[PRE-REGISTER HERE](#)

#### VIRTUAL EVENT TRIVIA:

**ALL ABOUT 2024**  
MONDAY, FEBRUARY 17  
8:00PM ET

After a few months of dormancy, Trivia is rising out of the ashes. Get out your diaries from last year and join us for a cutthroat – but very friendly – hour of trivia. There will be prizes! What other plans could you have for a Monday night that are this much fun?

[PRE-REGISTER HERE](#)

#### VIRTUAL EVENT MONTHLY

**MEMBER MEETUP**  
THURSDAY, FEBRUARY 27  
8:00PM ET

**SPECIAL GUEST:**  
**SHERRY HERMAN-HILKER**  
Special guest Sherry Herman Hilker is a Faculty member and a physical therapist who works with people with bleeding disorders. She will be hosting an Educational Session on PT, including a Q&A session!

[PRE-REGISTER HERE](#)

# LETTER FROM THE EDITOR



JOHNNA CESTA

Simone Weil was a French philosopher who lived from 1909 to 1943. She was a bright and inquisitive young woman who suffered many health problems that made it impossible for her physical body to keep up with her busy mind. She once wrote, "This world is the closed door. It is a barrier. And at the same time, it is the way through."

As sVWD patients, the world is full of doors that other people may not even notice. The bathroom door closing behind you when you leave the dinner party to try to discreetly control another nosebleed. The

school nurse's door closing for privacy to give a student an infusion before PE class. The looming, heavy, all too familiar automatic sliding doors of the ER. Even our bodies function as doors to how we engage with the world, with some doors and some days heavier than others.

Thankfully, the universe is full, maybe infinite, on our individual paths we will face many, many doors: barriers yes, but opportunity as well. To find this out requires a willingness to cross thresholds, to keep knocking, and to embrace all we are faced with, including those doors that just won't open. VWD Connect is the home to come back to at the end of the day. Once you cross the threshold of our Welcome mat, suddenly the door closing behind you won't be another barrier keeping you out, but an offering of an alternative way through.

For all of us, conference veteran or prospective new Member, our connections all start with that first knock. The bravery of spirit to be vulnerable and allow for community care is crucial to the makeup of our organization. It's both what sets us apart, and what binds the ties between us. It is the door through which our personal struggles become meaningful, and one that is worth the fight to keep open in each of us.

This year will be like others – life will happen, this, and that too, will pass. When life starts seeming like a series of closed doors, remember to knock on ours. You might even find reasons – companionship, validation, mutual care – to stay a while.

Happy 2025,

*Johnna*

*Remember*

I am doing my best today  
Some days are harder than others  
This is what I can handle right now  
I am working on accepting myself  
just as I am  
Now that I know, I can do better  
I am allowed to make mistakes  
I can try again tomorrow



**TAKEDA** is sponsoring a study that is 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 ATHN-dataset, 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](#)

**STAR THERAPEUTICS** (parent company to VEGA) is sponsoring a VWD Clinical Trial that is now enrolling for the VIVID 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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