



VWD CONNECT FOUNDATION

# NEWSLETTER

JANUARY 2025



Project Chair Dr. Tung Wynn, Foundation Executive Director Jeanette Cesta, and Medical Advisor Dr. Christopher Walsh

## VWD Connect Foundation Shines at ASH 2024

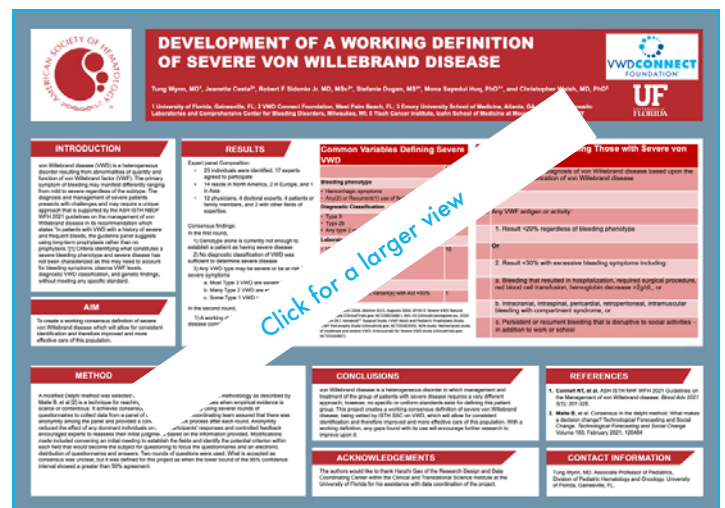
In the final month of 2024, the VWD Connect Foundation had the incredible opportunity to attend the 66th American Society of Hematology (ASH) Annual Meeting and Exposition in San Diego, California. With more than 30,000 attendees from across the globe, the ASH meeting is one of the largest gatherings of hematology professionals and researchers, making it an unparalleled platform for networking and collaboration.

The meeting was the perfect environment for the Foundation to connect in-person with current Faculty members, potential new Faculty, sponsors, and other stakeholders passionate about

advancing care for VWD patients. These connections are essential as they enable us to amplify the Foundation's voice, share our work, and stay informed about the latest research and treatments in the field.

Among the promising new developments shared at the meeting was the Foundation's own research, with the presentation of the poster, Development of a Working Definition of Severe Von Willebrand Disease, by the VWD Connect International Consensus Panel. Dr. Tung Wynn, project chair, proudly represented the panel and the Foundation during this significant milestone. This project, which began in early 2023, reflects months of dedicated effort to establish a unified definition that will guide the diagnosis and treatment of severe Von Willebrand Disease (sVWD). Sharing this work with the global hematology community was a powerful reminder of the impact patient organizations can have in not only advocating for and connecting patients, but helping to move the research needle as well.

Attending events like ASH reinforces the importance of collaboration. It's through such gatherings that we can connect with leading experts, build relationships, and continue to show the medical community the Foundation's commitment to serving patients by contributing essential research towards better knowledge and treatment of sVWD. ●



# JANUARY RESOURCES & EVENTS

## JANUARY 9 BALLOON ASCENSION DAY

This holiday commemorates America's first manned balloon flight, taking off from Philadelphia in 1793. Watch this short [VIDEO](#) to learn about one aeronaut's particularly adventurous celebration!

## JANUARY 11 LEARN YOUR NAME IN MORSE CODE DAY

If we were in the late 1800s and needed to telegraph the Foundation's name to new members, it would look like this:

...- .- .. / -.- -.- .-.- .-.- / ..- -.- -.- ..-.- .-.-

What does your name look like in Morse code?

Morse code			
A	• -	S	• • •
B	- • • •	T	-
C	- • - •	U	• • -
D	- • •	V	• • • -
E	•	W	• - -
F	• • - •	X	- • • -
G	- - •	Y	- • - -
H	• • • •	Z	- - • •
I	• •	1	• - - - -
J	• - - -	2	• • - - -
K	- • -	3	• • • - -
L	• - • •	4	• • • • -
M	- -	5	• • • • •
N	- •	6	- • • • •
O	- - -	7	- - • • •
P	• • - •	8	- - - • •
Q	- - • -	9	- - - - •
R	• - •	0	- - - - -

## JANUARY IS NATIONAL HOT TEA MONTH



As one of humanity's most ancient customs, tea has been around for almost 5,000 years! With countless variations and types, it can be intimidating to venture into the wide world of tea. [CLICK HERE](#) to check out this page with descriptions of ingredients and their uses to get the basics down!

## SCHOLARSHIP OPPORTUNITY

The Hemophilia Alliance Foundation has announced the Joe Pugliese Educational Award, a new scholarship program for first-time or returning college students with inherited bleeding disorders. [CLICK HERE](#) to learn more and apply.

## VIRTUAL EVENT MONTHLY MEMBER MEETUP THURSDAY, JANUARY 23 • 8:00PM ET

### SPECIAL EDITION: THE STATE OF THE FOUNDATION

Our January Monthly Member Meetup will be taken over by the State of the Foundation 2025. This annual meeting is a time for our community to regroup, reflect on last year, and learn about Foundation news, research, and events for 2025. There will be time to share questions or suggestions as well!

[PRE-REGISTER HERE](#)

## VIRTUAL EVENT BOOK CLUB: MOVIE EDITION

WEDNESDAY, JANUARY 8  
8:00PM EST

In *Inside Out 2*, Riley enters puberty and experiences new, more complex emotions, while her old emotions try to adapt.



[PRE-REGISTER HERE](#)

# Kayla Gregory



## How did you connect with the Foundation?

My family was introduced to VWD Connect through a longtime social worker at our local HTC. After attending several other conferences including NOW and NHF, my parents were excited to experience something more focused on sVWD and my unique journey.

## How old were you when your family joined VWD Connect? Do you remember your first conference?

I was 12 years old when my family first joined. One memory that stands out is participating in the clicker surveys, where I saw real-life statistics about my disorder for the first time. I also remember meeting people at completely different stages of their

lives, but all connected by a shared experience with VWD. It was a unifying and inspiring experience, even if I didn't fully understand the significance at the time.

## Where do you live? What would you recommend a first-time visitor do?

I live in Northern California. I highly recommend that first-time visitors explore all the awesome nature and state parks in the area, especially Lake Tahoe!

## How do you think growing up with your family being Foundation members has affected your experience growing up with sVWD?

I feel so lucky that my family found the Foundation so early in my sVWD journey. It gave us support and understanding that we couldn't find in the general medical world. For me, it's been empowering to connect with people who truly know what living with a severe bleeding disorder is like — something even my closest friends can't fully grasp. This experience has strengthened my confidence and provided me with a second family that holds a special place in my heart.

## As an athlete, do you have any advice for any of our younger patients who want to be involved in sports? Or maybe advice for nervous parents?

My first piece of advice is to not be afraid. The benefit of our disorder is the ability to take extra factor doses as needed, allowing us to participate

in athletics almost fully protected. Personally, I've done soccer, tennis, dance, gymnastics, skiing, and currently I am a member of the UC Davis Swimming & Diving team. While it's important to be cautious, it's also crucial to let your child enjoy life without feeling boxed-in by their disorder. Our first hematologist's advice was simple: no wrestling or tackle football, but everything else was fair game. I carry that mindset with me, prioritizing my happiness and interests while knowing I can take the necessary steps to stay safe.

## Last month, you traveled to Florida to sit on the Patient Panel at the Foundation's Provider Education Workshop. How was your experience attending that event?

I was honored to participate in the Provider Conference and learn directly from those who treat us, gaining a deeper understanding of their experience. It was encouraging to see how many providers are dedicated to our disorder. As someone planning to pursue a medical career with a focus on hematology, I was really interested in exploring the research and development opportunities in the field. There's been a strong desire for better treatment, but it's not always clear how to make that happen. The presentations at the conference helped answer those questions and gave me a sense of hope for what the future could hold. •

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



**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](#)

**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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